

DOWN SIDE UP: REPRESENTATIONS OF DOWN SYNDROME IN *BORN THIS WAY*

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## Abstract

Stereotypical media representations of people with disabilities reinforce stigma, resulting in dehumanization. Conversely, positive representations create counter narratives that challenge stereotypes and stigmatized information disseminated by the media. While some studies have explored media depictions of people with disabilities in general, there is a lack of research focusing specifically on Down syndrome. *Born This Way*, a reality TV show, provides an opportunity to explore mass media depictions of Down Syndrome. Qualitative content analysis was used to understand how *Born This Way* constructs representations of adults with Down syndrome. Four major themes were identified. *Born This Way*'s representation of people with Down syndrome is a departure from previous portrayals of people with disabilities. Specifically, people with Down syndrome speak for themselves and take back their narrative. Instead of dehumanizing individuals with Down syndrome, *Born This Way* represents people with Down syndrome as capable, independent, sexual, and multifaceted. Although *Born This Way* depicts differences associated with Down syndrome, these differences do not become more important than the person with Down syndrome. The portrayals in *Born This Way* have the ability to educate and influence viewer perceptions of people Down syndrome and positively influence viewers who have Down syndrome as well. Additionally, *Born This Way* seems to be offering a type of vicarious social support for parents of children with Down syndrome.

*Keywords: Down syndrome, Mass Communication, Reality Television, Parasocial Interaction*



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## **Introduction**

The media helps create, normalize, and perpetuate representations in society (Leavitt, Covarrubias, Perez, & Fryberg, 2015; Milkie, 1999). Our society is surrounded and consumed by media. Televisions, computers, cell phones, etc. and the internet have changed the way people communicate and learn about one another. Before these technological advancements, the world was a much smaller place and knowledge about people not within one's sphere was limited to a physical location. Now, technology has allowed individuals to connect with people on the opposite sides of the world, research unfamiliar concepts, and watch shows and movies about different cultures and places. Vicariously, individuals can experience and be exposed to groups of people that they have never interacted with face-to-face (Leavitt, et al., 2015). For example, people with disabilities have been ostracized and separated from the majority due to their "differentness," however, the media has begun to create a more inclusive atmosphere by depicting individuals with disabilities, despite their "differences." For instance, On February 7, 2018, Gerber announced their 2018 Gerber Baby was a boy named Lucas and Lucas has Down syndrome (Diaz, 2018; Klein, 2018). Lucas is the first baby with Down syndrome to ever win the contest (Diaz, 2018; Klein, 2018). Many parents of children with Down syndrome, including Lucas's own, hope that being a Gerber Baby will allow Lucas to spread awareness, acceptance, and break negative stereotypes and beliefs associated with Down syndrome (Diaz, 2018; Klein, 2018). Children with Down syndrome are deemed to be more acceptable for media representation than adults with Down syndrome, meaning that current trends in media representation like the choice of Gerber Baby are promising but still do not challenge the stigmatized status of adults with Down syndrome (Taylor, 2017).

Breaking this trend, in 2015, a new reality television show depicting seven adults with Down syndrome, entitled *Born This Way (BTW)*, had its debut. Unlike other fictional television shows that include individuals with Down syndrome, the reality aspect of *BTW* allows adults with Down syndrome to tell their own story. The lack of direct interaction with people and adults with Down syndrome in society results in a dearth of knowledge about people with Down syndrome, thus, media representations, like *BTW* serve as the only exposure some people have to individuals with Down syndrome (Leavitt, et al., 2015). The way *BTW* represents people with Down syndrome may cultivate either positive or negative influence on viewers based on message construction and framing (An, Paine, & McNiel, 2014; Schiappa, Gregg, & Hewes, 2006). Therefore, the messages contained in media representations are of utmost importance as they could serve to define an entire population.

## **Chapter 1: Literature Review**

The messages we receive through the media help perpetuate social and cultural norms (Leavitt, et al., 2015; Milkie, 1999). Media influence is compounded by constructs such as social distance and parasocial interaction. These important concepts are expanded below. Repeated exposure to stereotypical representations have consequences for viewers and the populations represented (Dixon & Azocar, 2007). Therefore, common representations of people with disabilities in the media are outlined and discussed. The reality television genre claims to provide images of ‘real’ people to the public and these representations whether accurate or not influence viewer construction of reality (Biressi & Nunn, 2005). As a reality television about a minority group, *BTW* could help influence the public’s attitudes about people with Down syndrome (Schiappa, Gregg, & Hewes, 2006).

### **Cultural Impact and Stigma**

Culture provides a set of rules, values, and perspectives that function as the underlying mechanisms that guide individual worldview (Hofstede, 1984). Hofstede (1984) defined culture as, “The collective programming of the mind which distinguishes the members of one group or society from those of another” (p. 82). This “collective programming” is brought to life in buildings, art shows, television etc. (Hofstede, 1984). Fischer (2009) described the passing of key cultural values and knowledge as a “socialization process” from older generations to younger (p. 29). These socially constructed belief systems act as a guide or “rule book” for what values, behaviors and goals are appropriate and “good” (Fiske, 2002). Cultures and societies use these rules to categorize, label, and define normal, beautiful, good or bad and thus establish norms (Goffman, 1963). By defining a norm, cultures define what is deemed “normal” thereby simultaneously creating an abnormal category (Goffman, 1963). People who are labeled

“abnormal” are stigmatized and excluded or separated from society (Goffman, 1963). Baumann (2007) defined stigma as, “A distinguishing mark, establishing a border between a stigmatized person and others attributing negative characteristics to this person” (p.131). The strength of the stigma is determined by cultural values (Kayama & Haight, 2011). This line in the sand separates “us” from “them” and very clearly denotes what is good and normal and what is bad and different.

Stigmatized groups, such as African Americans, and those with disabilities have a long history of fighting to escape their stigmatized status and be seen as equal or human in America. The color of skin was once used to separate the elite from the slave. People of color were enslaved, hunted, mistreated, killed, and discriminated against due to the stigma associated with the color of their skin. Fast forward to today and hate crimes due to this stigma still, exist. Likewise, people with disabilities, have long been stigmatized in Western culture. In the past, people with disabilities were seen as abominations, mistakes, and were institutionalized or presented as the main attraction in a freak show (Hayes & Black, 2003). Crowds gathered to gape and laugh at the oddities found at these shows (Hayes & Black, 2003). People in these freak shows were dramatized and sold as a wonder, horror, or curiosity (Hayes & Black, 2003). Whether locked in an institution or locked in a cage at a freak show, individuals with disabilities were treated as a stigmatized, less than human population (Goffman, 1963). In the late 1950s, early 1960s, children with disabilities were showcased on television to prick viewers hearts and garner money for charities like the Muscular Dystrophy Association (Hayes & Black, 2003; Shapiro, 1994). These children were seen as helpless because of their disability and thus needed to be saved by someone without a disability (Hayes & Black, 2003; Shapiro, 1994). The results of stigma exemplified above, show a direct divide between those without disabilities and those

with disabilities, “us” and “them.” This divide separates the “normal” from those perceived as “different” and creates a sense of distance between the two groups.

As defined by Greenwald & Banaji, (1995) “A stereotype is a socially shared set of beliefs about traits that are a characteristic of members of a social category” (p. 14). These traits can be positive or negative and are often broadly applied to anyone who is deemed to fit into the specified category (Mackie, 1973). Due to the pervasive use of stereotypes and majority preference, the media often represents minority groups inaccurately (Leavitt, et al., 2015). One common negative stereotype associated with African Americans for example, depicts African Americans as criminals (Weaver, 2016). Dixon and Linz (2000), found that the majority of news on television showed African Americans as criminals. Constant exposure to messages that associate African Americans with violence and crime adds credibility to the stereotype and can create a cognitive connection between crime and African Americans (Dixon & Azocar, 2007). This process is known as priming and has been defined as, “the process by which recently activated information about a group (e.g., stereotypes) is used in making subsequent judgements” (Dixon & Maddox, 2005, p.1556). The longer the exposure people have to stereotypical messages, the more these messages impact and prime viewers associations (Dixon & Maddox, 2005). News articles reporting titles like this 2017 article “South Carolina Police Officer Sentenced for Shooting an Unarmed Black Man” and the rise of a Black Lives Matter group dedicated to finding justice for African Americans that are victims of violence and racism are just two examples what happens when the color of skin and crime are associated (Black Lives Matter, n.d.; Hansen, 2017). Black Lives Matter grew from rage at the police killing of Trayvon Martin and the exoneration of his murderer (Black Lives Matter, n.d.). While these examples point to a larger issue of racism in America, the subliminal messages of stereotypes and

oversaturation of African Americans as criminals in the media play a role in this narrative and this primes viewers to make stereotypical conclusions (Dixon & Azocar, 2007; Dixon and Linz, 2000; Dixon & Maddox, 2005; Weaver, 2016).

People with disabilities are also subject to inaccurate stereotypical portrayals in the media (Leavitt, et al., 2015). People with disabilities who have disfigurements are often represented as villains in popular culture (Leary, 2017). Supreme Leader Snoke in *The Last Jedi*, Captain Hook in *Peter Pan*, and Freddy Krueger, in *The Nightmare on Elm Street* franchise, all have some kind of facial or limb deformity and are all evil villains. Repeated exposure to representations like the characters above can prime viewers to associate evil and disability (Dixon & Maddox, 2005). For example, a recent news article shared the story of Sophia, a nine-year-old born with both facial and limb deformities (Willingham, 2018). Due to the way Sophia looks and her need for constant care, Sophia and her family often face the results of societal discrimination and stigma towards people with disabilities (Willingham, 2018). Instead of seeing a human child, people have lashed out against Sophia's existence on Twitter, sending tweets with messages carrying themes which presume she is a burden on society and ultimately sentence her to death (Willingham, 2018). One person used a picture of Sophia to advocate for abortion (Willingham, 2018). Goffman (1963) stated it this way, "By definition, of course, we believe the person with a stigma is not quite human. On this assumption, we exercise varieties of discrimination, through which we effectively, if unthinkingly, reduce his life chances" (p.5). Sophia's mother echoes this sentiment, "I think many times, people don't even view Sophia is a person." (Willingham, 2018, para 6). Exposure to stigmatized depictions of disability reinforces the notion that people with disabilities are not as valuable as 'typical' people (Goffman, 1963). Just like constant exposure to the association of African Americans and crime adds credibility to the stereotype, constant

exposure to depictions of people with disabilities as evil or less valued adds credibility to the stereotype and creates a cognitive association between evil and disabilities (Dixon & Azocar, 2007). Although the media is not the only entity responsible for purveying the idea that disability and evil are connected, the media's depiction of minority groups helps establish and perpetuate societal beliefs and cultural norms (Leavitt, et al., 2015; Milkie, 1999). Consequently, the influence of media representations is clear, the way minority groups are portrayed in the media matters.

### **Social Distance**

The way people are depicted on television informs the population about how much distance they should put between themselves and others. "Social distance defines the distance one wants to have between oneself and another person in a social situation" (Baumann, 2007, p.132). People are often more comfortable around others who are in some way similar to themselves (Ouellette-Kuntz, Burge, Brown, & Arsenault, 2010). If one perceives someone to be like themselves, this will result in less social distance between the two (Oullette-Kuntz, et al., 2010). If an individual perceives that a person or group is vastly different from themselves, social distance increases (Bauman, 2007). In low social distance relationships, people are connected and willing to establish a relationship (Bauman, 2007). In high social distance relationships, fear of difference and the unknown eradicate the desire for a relationship (Bauman, 2007). This obvious separation of "us" and "them" has carried on through the years and still impacts attitudes toward disabilities. Although people with disabilities are no longer hidden in institutions, the separation of "us" and "them" continues and thus increases social distance. Taylor (2017) examined how people reacted to individuals with Down syndrome in advertising. The majority of individuals included in the study disclosed that their only interactions with individuals who had disabilities



occurred by happenstance (Taylor, 2017). The participants in the study did not actively seek to interact with people who had disabilities, thus interactions were of necessity and stayed at the surface level (Taylor, 2017). Due to the surface interactions, people were fearful and hesitant to interact with people who had disabilities (Taylor, 2017). Lack of interaction with people who have disabilities, increases uncertainty and fear of difference, thereby increasing social distance (Bauman, 2007; Oullette-Kuntz, et al., 2010; Taylor, 2017). The lack of exposure leaves individuals susceptible to media priming; unable to compare television depictions to the reality of knowing someone with a disability.

### **Parasocial Interaction**

Parasocial interaction is a naturally occurring phenomenon that transpires when watching television and results in a perceived interpersonal bond between a viewer and television character (Perse & Rubin, 1989; Rubin & McHugh, 1987). People who have parasocial interactions with television characters see the mediated figure as a personal friend and they respond to these characters as they would a friend (Giles, 2002). The viewer feels informed enough to make character judgments about these television characters (Giles, 2002). Although animated and fantasy characters have also elicited parasocial relationships, authenticity or the realistic nature of a character influences the appeal of a parasocial relationship (Giles, 2002). If the viewers perceive that television characters are talking directly to them, parasocial interaction can increase (Schramm & Hartmann, 2008). Thus, the documentary type interviews that are used in *BTW*, where the cast talk directly to the camera may increase the parasocial interaction viewers will feel with the cast. While these parasocial relationships occur often with television characters, the implications of parasocial interaction on attitudes and perception are vast (Perse & Rubin 1989). For groups that are not often depicted in the media, parasocial interaction is a

way to connect with, influence attitudes, and challenge stereotypes about these individuals (Schiappa, Gregg, & Hewes, 2006).

Previous research supports the argument. For example, Schiappa, Gregg, and Hewes, (2006) studied the impact of positive representations of homosexuals in the media. Television shows that portray minority or stigmatized groups can serve as a spotlight into an unknown community or world (Schiappa, Gregg, & Hewes, 2006). The parasocial hypothesis concludes that vicarious television interaction with a stigmatized group can form a parasocial relationship and thus decrease or increase the stigma or prejudice a viewer feels for the stigmatized group (Schiappa, Gregg, & Hewes, 2006). The way minority groups are represented in the media can result in a positive or negative correlation between the viewer and the minority group (Schiappa, Gregg, & Hewes, 2006). The researchers used the sitcom *Will and Grace* to determine if the depiction of gay characters could influence attitudes (Schiappa, Gregg, & Hewes, 2006). The results of this study indicate a significant relationship between the existence of parasocial interaction and how often the show was viewed (Schiappa, Gregg, & Hewes, 2006). This relationship resulted in lowered prejudice between the viewer and gay men (Schiappa, Gregg, & Hewes, 2006). An alternative explanation for these significant results could be that people who have familiarity and positive relationships or attitudes about individuals who are gay, “are more likely to watch the show and experience parasocial interaction with its gay characters” (Schiappa, Gregg, & Hewes, 2006, p. 10). Even so, the findings of this study clearly indicate that positive media depictions and parasocial interaction can positively influence viewer beliefs about a minority population (Schiappa, Gregg, & Hewes, 2006),

Clearly, media representations of minority cultures are powerful. The influence and impact of media messages can create negative associations or positive connections. Parasocial

interaction may help bring people in contact with minority characters whom they have never interacted with face to face (Schiappa, Gregg, & Hewes, 2006). Negative stereotypes and depictions can also increase social distance. Without real life interaction with people who have disabilities, viewers have no real life comparison for media representations and media priming. The depiction of a minority, such those who have disabilities, can influence how people without disabilities think about and interact with this minority population in real life. Thus, it is important to understand how people with disabilities are portrayed in the media.

### **Media Representations**

Media representations of people with disabilities are fraught with controversy. Characters with disabilities are prominently seen in movies and on television; however, the actors playing 95% of these roles do not have a disability (Woodburn & Kopic, 2016). The lack of self-representation in television limits and changes the minority narrative to reflect the way the majority imagine their experience. While white actors putting on ‘black face’ and pretending to be African American sparks outrage, the practice of ‘crip face’ or ‘cripping up’ where actors pretend to have a disability, is accepted and rewarded (Ruderman Family Foundation, 2017; Smith, 2015; Woodburn & Kopic, 2016). Able-bodied actors that participate in criping up are often the receivers of praise and awards for their portrayal of disability (Smith, 2015). For example, both best actress and best actor Oscars in 2015, went to non-disabled actors playing characters with disabilities (Smith, 2015). Eddie Redmayne received an Oscar for his role as Stephen Hawking who has Lou Gehrig’s Disease, also known as ALS, in *The Theory of Everything* and Julianne Moore played a woman with Alzheimer’s in *Still Alice* (Rettner, 2018; Smith, 2015). Acting roles that include disability are considered “Oscarbait” and the more crip face is celebrated the more abled actors will be pursuing roles that include a disability (Smith, 2015). The lack of

depictions and actors that truly understand and have experienced disability has caused stereotypes and misconceptions to be mainstreamed through the media. Mainstreamed portrayals of individuals with disabilities are often limited in the number of character roles and the disability instead of the person's humanity is the main focus of the representation (Harnett, 2000 & Hayes & Black, 2003). Common themes associated with the depiction of people with disabilities in the media include the following: Villain/Evil, Super Crip, Incapable of Sex vs. Abnormal Sexual Desires, Monster, Pitiful, Maladjusted, Worthless/Better off Dead, Burdensome and Confinement.

### **Villain/Evil.**

As discussed above, people with disabilities are often depicted as wicked (Barnes, 1992; Longmore, 2003). Two Face and Joker from *Batman*, Darth Vader from *Star Wars*, Voldemort from *Harry Potter* and Dr. Poison from *Wonder Woman* all have two things in common: one, they are villains and two, they all have flawed or different facial appearances (Harnett, 2000; Leary, 2017). The juxtaposition of the beautiful, flawless Wonder Woman and the disfigured Dr. Poison provide a clear message to the audience of who is "good" and who is "evil" (Leary, 2017). Tom Riddle is a nice looking young man, comparable to any other in the magical world of Hogwarts until his desire for power and evil heart eventually disfigures his appearance so that the inside reflects the outside (Leary, 2017). This common connection between disfigurement and villainy primes the viewer to see people who look abnormal as evil.

### **Super Crip.**

The supercrip stereotype which shows people with disabilities as persevering super people who if they put their mind to it can beat their disability (Harnett, 2000). The super crip theme portrays people with disabilities as inspiration and creates a distinctly higher expectation in the eyes of

the non-disabled for everyone with a disability (Toutellotte, 2015). For example, in the *Book of Eli*, the character accomplishes many amazing feats such as taking on several men at once and traveling great distances (Silver, Washington, Johnson, Kosove, Valdes, Hughes, & Hughes, 2010). It is not until the end, when Eli is reading Braille, that the viewer realizes he is blind (Silver, et al., 2010). This realization makes Eli a superhero of sorts who not only accomplishes great things but does so while blind. *Glee*, a popular television show, uses the super cripple stereotype (Toutellotte, 2015). A recently injured character named Quinn discusses her paralysis and is determined to walk again and succeed even in the face of her disability (Toutellotte, 2015). Quinn's positivity reflects an underlying belief of the super cripple theme: sometimes beating a disability just means positively accepting and living with a disability (Toutellotte, 2015). Automatically then, those who do not rise above their disability are seen as lazy or burdensome.

### **Incapable of Sex vs. Abnormal Sexual Desires.**

The belief permeated in media representations is that people with disabilities are incapable of normal sexual relations (Harris, 2002). Often people with disabilities are portrayed as asexual or unable to have sex (Barnes, 1992; Harris, 2002). In the television show *Downton Abbey*, a prominent character, Matthew, returns from the war paralyzed (Richmond, 2016). Matthew's disabled identity impacts how he understands his sexuality (Richmond, 2016). He is convinced that he is unable to provide his fiancé with children and decides to break the engagement to save her from the burden of his care (Richmond, 2016). This stereotype purveys the message that people with disabilities are sexually stunted, incapable and unable to have sex (Barnes, 1992). Specifically, these depictions reinforce the notion that paralysis is synonymous with losing sexual identity (Longmore, 2003). Variations of this theme show people with disabilities as sexual predators making beautiful women their victims (Longmore, 2003). The Phantom in the

*Phantom of the Opera* desires Christine, the beautiful singer to the point of bringing her down to his “lair” and making her afraid of loving someone else (Webber & Schumacher, 2004). This stereotype strips people with disabilities of sexuality or makes them sexual predators, thereby stripping them of their humanity.

### **Monster.**

This theme is driven by the fear and hate of difference and assumed deformity (Longmore, 2003). The extreme visible disfigurement help mark and create the perception of a monster (Longmore, 2003). The person with a disability is sometimes only a monster due to their appearance (Longmore, 2003). From mistreatment of people with disabilities in freak shows and their subsequent portrayal as “monsters,” to crowds chaining and jeering at people with disabilities in film, the monster theme has been purveyed through both real life and media depictions (Barnes, 1992). An example of this monster theme is the *Hunchback of Notre Dame*. The Hunchback is locked away in the tower due to his repulsive appearance, he has no friends and no one to love him (Hahn, Trousdale, & Wise, 1996). His attempt to be outside with “normal” people ends in him being chained and covered in food and drink that people threw on him (Hahn, Trousdale, & Wise, 1996). Quasimodo then learns the importance and safety of his high tower (Hahn, Trousdale, & Wise, 1996). This example connects to the pitiful theme as viewers without disabilities see Quasimodo’s disfigured appearance and pity him knowing he cannot be fully accepted into society due to his disability (Longmore, 2003). Like the Villain/Evil theme, stereotypical representations of people with disabilities as monsters based on appearance creates a connection between abnormal disfigurement and evil internal characteristics.

### **Pitiful.**

Pity in Hollywood films depicting people with disabilities further separate people with disabilities from people without disabilities and reinforce their “difference” (Hayes & Black, 2003). Hayes & Black (2003) found that many films that included individuals with disabilities told their stories through a lens of pity. “Pity is an emotionally conditioned social response which marginalizes those with disabilities and better serves the interests of those who show pity than it does the object of their pity” (Hayes & Black, 2003 p. 115). One of the most famous examples of this theme is the Muscular Dystrophy Association Labor Day Telethon hosted by Jerry Lewis (Shapiro, 1994). The telethon framed disability as a tragedy whose victims were innocent, miserable, sick, children, destined to die and therefore, desperately in need of help from supporters (Shapiro, 1994). The images like that of a sad broken children trying to walk despite crooked legs were successful fundraisers (Shapiro, 1994). Representations of pity remind viewers that the safety and care of people with disabilities rest on the compassion of people without disabilities (Barnes, 1992).

### **Maladjusted.**

This stereotype constructs disability as an individual psychological issue (Barnes, 1992; Longmore, 2003). People with disabilities are often portrayed as unable to adjust to the new reality of disability, becoming depressed, bitter, and distant (Longmore, 2003). In this way, people with disabilities are portrayed as not having the ability to accept themselves and need someone without a disability to educate them (Longmore, 2003). Thus, the person without a disability is depicted understanding what people with disabilities really need to hear (Longmore, 2003). The television show *Glee* depicts the character Artie (a non-disabled actor) who is in a wheelchair, as needing advice from a non-disabled individual so that Artie can understand why

he has a disability (Toutellotte, 2015). After a tumble from his wheelchair due to a slick wheelchair ramp, Artie wants to walk again (Hodgson & Shankman, 2012). Artie is guided through a dream sequence where he is magically able to walk by a nondisabled individual who shows Artie the impact on his friends if he was not a wheelchair user (Toutellotte, 2015). This theme attributes Artie's problem as not one brought on by the school's lack of attention to Artie's needs as a wheelchair user, but to Archie's inability to accept himself as a wheelchair user (Barnes, 1992; Longmore, 2003). This stereotype serves to undermine an individual with a disability's independence, ability, and autonomy.

### **Worthless/Better off Dead.**

Another common film stereotype portrays individuals with disabilities as incapable of being an active member in everyday life and interactions and thus show people with disabilities lives as worthless (Safran, 1998). Will a young, active, carefree man, becomes paralyzed after an accident and decides that life with a disability is not actually living (Rosenfelt, Owen, & Sharrock, 2016). Will's existence and death in *Me Before You* is used to help reshape his caretaker's life, thus showing another common theme in disability representation: the theme of the character with a disability only existing to improve the life or teach a lesson to the non-disabled character (Gilbey, 2016). Although his caretaker tries to show him that he has a wonderful life, Will flies to Sweden to die with the help of assisted suicide (Rosenfelt, Owen, & Sharrock, 2016). Other films that repeat this theme are *Million Dollar Baby*, *Who's Life is it Anyway*, and *The Sea Inside* (Gilbey, 2016). All of these films depict disability in such a way that death becomes better than life with a disability (Gilbey, 2016).



### **Burdensome.**

Instead of focusing on the person with a disability, this theme showcases the sacrifice of those who are burdened with the task of taking care of someone with a disability (Barnes, 1992; Black & Pretes, 2007). This theme is often connected to the “better off dead” theme and shows the person with a disability sacrifice their lives for the sake of their families and loved ones (Longmore, 2003). The lack of ability to function in one’s community often isolates individuals with disabilities (Longmore, 2003). The limited representations of people with disabilities in everyday life reinforce the stigmatized beliefs of useless dependence (Longmore, 2003). Again, this theme is seen in *Me Before You*. Although Clark, Will’s caretaker, is in love with Will, he does not want her to be burdened with him and miss out on a relationship with someone without a disability (Rosenfelt, Owen, & Sharrock, 2016). While this theme is included in media depictions, the belief that people with disabilities are harmful to society stays alive (Barnes, 1992).

### **Confinement.**

While the confinement theme is steeped in pity and connected to the burdensome theme, it provides an insight into the construction of ability through the piteous eyes of the non-disabled majority (Hayes & Black, 2003). The theme of confinement is included here because of its relevance to the current research. People with disabilities who are represented as villains are often isolated or confined in a mask and individuals with disabilities framed as pitiful are depicted as confined in their disability. Actors or people who are wheelchair users are often defined as “confined to a wheelchair” and due to society’s level of accessibility these wheelchair users are often confined by the society around them (Hayes & Black, 2003). These portrayals hold on the hope of complete independence and freedom for those with disabilities (Hayes &

Black, 2003). People with disabilities that cannot be overcome or rehabilitated are often erased from the world of Hollywood (Hayes & Black, 2003). Facilitation of independence with small goals and help where it is needed is not often represented (Hayes & Black, 2003). When movies show that overcoming the disability is impossible, viewers are often left with pity (Hayes & Black, 2003). While the confinement shown in the beginning of these movies is often shown negatively, the confinement at the end is given a rosy hue (Hayes & Black, 2003). In *Sybil*, a film depicting a woman who has schizophrenia, the audience is led to see that Sybil should live in a mental institution, that a mental institution is the proper place for her (Hayes & Black, 2003). The message becomes without the walls around them, people with disabilities would be severely inhibited in society (Hayes & Black, 2003).

The focus on disabilities as “dramatic, dangerous or challenging” reinforces the “difference” or stigmatized status of people with disabilities (Harnett, 2000, p. 22). Significantly, those that depict individuals with disabilities can serve to educate the viewers on people with disabilities (Hayes & Black, 2003). Hollywood films help create knowledge of individuals with disabilities and help define their status in society (Hayes & Black, 2003). Parasocial interaction influences viewers based on messages that either increase or decrease stigma (Schippia, Gregg, & Hewes, 2006). Depictions of individuals with disabilities as a multifaceted person are lacking and thus inaccurate or stereotypical media messages about individuals with disabilities remain unchallenged (Barnes, 1992; Harnett, 2000). The more viewers are exposed to these stereotypical messages, the more these messages will prime their understandings and interactions with people who have disabilities (Dixon & Maddox, 2005). Exposure to negative, dehumanizing, stereotypical messages about people with disabilities, results in an increased social distance

between the viewer and those depicted as different (Baumann, 2007). Therefore, the need for positive messages about people with disabilities is imperative.

In the midst of the negative representations, there have been some positive depictions of actors with disabilities in the media. In 1976, Linda Bove, a deaf actress was featured on Sesame Street as a librarian (Shephard, 2007). *Life Goes On* included cast member Chris Burke, a man with Down syndrome, who played “Corky” (Shephard, 2007). Geri Jewell became well known as “Cousin Geri” on a show called *The Facts of Life* (Sunderland, 2015). Shephard, (2007), points out that many characters with disabilities have also been included in *Star Trek*. While there is a lack of media depictions of individuals with disabilities living out their normal everyday lives, several fictional and nonfictional television shows have attempted to show characters with disabilities in a ‘normal’ family (Harnett, 2000). The three examples of fictional television dramas below represent positive depictions of individuals with disabilities. The characters included in the discussion below are played by individuals with a disability, thus rejecting crip face and allowing individuals with disabilities to share their own truth.

*Switched at Birth*, is a show about two girls who were accidentally given to the wrong family at birth (Perry, 2017). One girl, Bay is hearing, and the other Daphne is deaf (Perry, 2017). This television show employs actors with disabilities in the roles of characters with disabilities and used the show platform to showcase Deaf culture (Perry, 217). The television show even had an episode shot entirely in American Sign Language (ASL) with subtitles. Although *Switched at Birth* cast well-known Deaf actress Marlee Matlin, among others Deaf actors, to stay away from crip face, controversy ensued when Katie Leclerc, an actor with Meniere’s disease which causes oscillating loss of hearing was cast as the main deaf character, Daphne (Cooper, 2011; Szymanski, 2016). A petition was created to recast the role of Daphne to

a person who identified as Deaf (Szymanski, 2016). This petition did not receive the number of signatures needed, and Katie Leclerc stayed in the role (Szymanski, 2016). While this show does have lots of soap opera drama with constant breakups and makeups, it still brings disability issues into public view (Perry, 2017).

*Game of Thrones* has also provided the public with some positive portrayals of disability (Donnelly, 2016). Tyrion Lannister, a character with dwarfism, played by an individual with dwarfism is different than the depictions of dwarfs in other films (Donnelly, 2016). Tyrion Lannister is depicted as a human who is different and has to deal with the prejudice of an able society (Donnelly, 2016). While Tyrion is constantly discriminated against, he is active in trying to gain family affection and approval and used his intellect to further family pursuits (Donnelly, 2016). Tyrion is firm in his identity and knows his strengths (Donnelly, 2016). This representation of dwarfism is incomparable with the Munchkins from *Wizard of Oz* or the happy workers from *Snow White* (Donnelly, 2016). Instead of one dimensional, Tyrion is a multifaceted character with intelligence, flaws, a desire for power and a sense of mortality (Donnelly, 2016). This character defies stereotypes of pity, villainy, and dwarfism and is shown as a human with many sides, regardless of his stature (Donnelly, 2016). Although *Game of Thrones* depicts Tyrion as a multifaceted character, other characters with disabilities are tainted by stereotypes (Donnelly, 2016). For instance, after becoming paralyzed, Bran receives magical powers which shows the superhuman or super cripp overcoming a disability with magical powers (Donnelly, 2016; Ulaby, 2017). Another character named, Jaime Lannister sees Bran's life as useless and advocates for death over disability using the worthless/better off dead theme (Lambert, 2015). Later, Jaime's hand is cut off and unable to fight he is forced to rely on others for help which could be related to the burden theme (Donnelly, 2016). While Tyrion's representation is

positively portraying disabilities, the same can not be said for the rest of the characters who have or gain a disability in the show (Donnelly, 2016).

*Speechless* is a television show about a normal family living their everyday lives, one of the family members, Micah, just happens to have Cerebral Palsy (Perry, 2017). Unlike past depictions, this show sought the experience and knowledge of people with disabilities and cast people with them to play the characters with disabilities (Perry, 2017). The show tackles issues related to disabilities, such as a mother's battle to get her son everything he needs for a quality education and brings up disability misrepresentations creating dialogue about 'inspiration porn,' which portrays people with disabilities as existing only to make those without disabilities feel better about themselves and their abilities (Perry, 2017).

Unlike the previous examples, *Little People, Big World* is not a soap opera or family drama but rather a reality television show. Reality television is set apart from soap operas whose characters may reflect real life but are not seen as "real" and documentaries which are often perceived as real but lack the format of a television show (Müller, Klijn, & Zoonen, 2012). *Little People, Big World* is a reality docu-series that depicts the lives of the Roloff family (Humphries, 2011). Matt and Amy Roloff are adults with dwarfism and they have four children (Humphries, 2011). Of the four children, only one of them has dwarfism (Humphries, 2011). The Roloff family's everyday life is depicted on screen and the viewers are able to follow the family and see the reality of living in a world that does not accommodate for their stature (Humphries, 2011). Individuals with dwarfism see this reality television show as a positive representation that helps reduce the stigma surrounding dwarfism (Humphries, 2011). *Little People, Big World* has the power to define dwarfism in both the eyes of the those with dwarfism and the public (Humphries, 2011). This reality television show's representation caused a ripple effect and

opened the door for other positive media portrayals that can educate the public about the ‘real’ lives of those with dwarfism (Hayes & Black, 2003; Humphries, 2011).

### **Reality TV and Born This Way**

Instead of actors in a role, reality television shows depict individuals living their everyday lives (Frisby, 2004). There are various types of reality television shows and therefore many definitions as well (Orbe, 2008). Dowd (2006) defined reality television as “a genre of programming that, whether scripted or not, offers its viewers an ostensibly real depiction of both individuals and issues” (p. 18). *BTW* fits into reality television in the category of docu-series or “documentary-style reality TV shows” (Orbe, 2008, p. 348). This type of reality television shows often showcases individuals as they live their everyday lives and endure happiness and hardship (Orbe, 2008). However, people living this reality know they are being filmed (Hall, 2006).

Hall (2006) conducted focus groups to determine what people thought about reality television and if they determined the events that occurred in them to be reflective of real life. Hall (2006) found that the majority of people felt reality television showcased real people whose experiences and life events were “uncharacteristic” or vastly different than other people (p.200). For instance, a reality show about a family having 7 babies at once, is not indicative of the experiences that the majority of women have with birth (Hall, 2006). Additionally, editing was pointed out as creating an unrealistic view of events (Hall, 2006). Editors can cut or piece scenes together to create the kind of feeling or scene they want to portray (Hall, 2006). However, the presence of people who were not actors and the perception that some of the shows were unscripted added an element of reality to these otherwise unrealistic shows (Hall, 2006). Reality television shows were found to be appealing due to “perceived novelty” (Hall, 2006, p. 202). In fact, “The current participants’ comments suggest that novelty contributes to enjoyment of the

shows because it makes the outcomes of the show less predictable, thereby increasing suspense and involvement (Hall, 2006, p.210).

Freak shows used the novelty of abnormal bodies to draw crowds (Backstrom, 2012). While these types of freak shows are no longer common, they have found a new home in movies and television shows (Backstrom, 2012). “The "reality" genre has made physical anomalies central to their programming” (Backstrom, 2012, p.683). Similar to the way freak shows drew people to see abnormal bodies, television programs including people with disabilities draw people due to their difference (Backstrom, 2012). Even so, reality shows that feature previously stigmatized populations can be used to reclaim group identity and debunk stigma (Backstrom, 2012). However, these representations of people with disabilities are impacted by their stigmatized status (Backstrom, 2012).

Reality television then creates a semblance of reality based on audience perception of “real” (Müller, Klijn, & Zoonen, 2012). Hall (2006) describes what influences the perception of ‘real,’ “The conceptualization of a realistic portrayal as one that portrays attributes that are representative of ‘regular’ people or to a large proportion of a real-world population” (p. 632). Realistic portrayals in the media needed to be common enough that viewers feel the scenario could actually take place in their own lives (Hall, 2003). The perception of reality and influence have a positive correlation (Busselle & Greenberg, 2000). The more realistic a show is perceived to be, the more the communication constructs and messages in the show are likely to influence viewer perception (Busselle & Greenberg, 2000). Some television viewers believe that “non-fiction television should ‘tell it like it is’” (Biressi & Nunn, 2005, p. 9). Thus, reality TV, is expected to create an even more realistic feel as they use real people, real words and seek to reveal scenes of everyday life (Biressi & Nunn, 2005). Whether ‘real’ or not the messages

constructed in reality television are helping to create knowledge about what reality actually contains (Biressi & Nunn, 2005). The popularity and reach of this genre may provide reality television with the ability to create an impact on society that is larger than other types of television shows (Müller, Klijn, & Zoonen, 2012).

A recent addition to the reality television genre is a show called *Born This Way (BTW)*. Jonathan Murray previously produced *The Real World*, the first reality television show to utilize personal confessions, and thus introduced a new kind of reality television show to viewers (Klein, 2015). Jonathan Murray, now the producer of *BTW*, wanted a way to magnify the voices of minority and outcast groups (Grobar, 2017). *BTW* ignores invisibility of the past and provides people with Down syndrome a voice to say, as John an adult with Down syndrome featured on *BTW* said, “I’m here. I’m alive. I am human” (Korkoian, 2015, 35:58-36:00). While negative imagery is often associated with reality television, Murray seeks to provide previously silenced populations with an opportunity to speak for themselves (Grobar, 2017). To better represent and interact with the cast, both Murray and the director, Lauren Korkoian, delved into the world of disabilities and began learning all they could (Grobar, 2017). *BTW* is created differently than other television reality shows, in that shooting often occurs over a longer period of 17 to 18 weeks (Grobar, 2017). While the goal is to capture the reality of living with Down syndrome, the television show is unscripted and cut like a documentary (Appelbaum, 2017; Grobar, 2017). As such, the reality television show has been dubbed a “docu-series” (Appelbaum, 2017, para. 1). This is the first paper to delve into *BTW* to better understand the nature of *BTW*’s representation of Down syndrome and the kind of impact, the show is creating.

*BTW* follows the lives and everyday interactions of seven adults with Down syndrome. These adults have different perspectives, personalities, and goals. Cristina, age 25, seems to be



the mother of the group. For example, whenever someone is sad or has a problem, she is the first one to provide encouragement and comfort (Korkoian, 2015). Cristina is Hispanic and in a steady relationship and hopes to get married and live independently (Korkoian, 2015). Steven, age 24, works at Angels Stadium and hopes to have a car, independence, and a girlfriend someday (Korkoian, 2015). Steven has Mosaic Down syndrome, a rare condition that provides him with higher functioning than a typical individual with Down syndrome (Korkoian, 2015). Rachel, age 32, has been a mailroom assistant for several years, is boy crazy, dreams about getting married, and loves rated R movies (Korkoian, 2015). Elena, age 28, is Japanese and was born in Tokyo. She loves poetry, acting, and cooking. Elena seems very sensitive about Down syndrome (Korkoian, 2015). John, age 28, is African American and is an aspiring rap artist and songwriter (Korkoian, 2015). Sean, age 21, is an avid golfer and has won many trophies in the Special Olympics (Korkoian, 2015). He would like a girlfriend and calls himself a “ladies man” (Korkoian, 2015). Last but not least, Megan, age 22, was a cheerleader in high school, has her own business, is attending college, is a public speaker, and has a boyfriend. She dreams of being a film producer and creating a documentary about Down syndrome (Korkoian, 2015). Most of the cast for *BTW* knew each other before the show began (Grobar, 2017). The seasons were created with the goals of each adult with Down syndrome in mind (Grobar, 2017). For instance, meetings with parents revealed that living independently was something Sean’s parents wanted him to experience, then steps were taken to make these goals happen on film (Grobar, 2017). However, not every part of the show is planned, sometimes the camera is rolling, as life happens (Grobar, 2017). These unplanned moments often create audience connection (Grobar, 2017). For instance, in one episode with the help of an aide that did regular check-ins, Steven and Sean live together for several months (Grobar, 2017). When they finish this trial living situation, Sean

turns to thank the aide and his words really show the impact and the importance of what the aide helped them do (Grobar, 2017). There is no doubt that *BTW* is causing an impact, but the size and nature of the impact is not clear (Appelbaum, 2017). The show has already aired three seasons since 2015 and is currently developing their fourth season.

While parasocial interaction can occur with both fictional and nonfictional characters, reality, Tsay-Vogel, and Schwartz (2014), postulated that parasocial interaction with authentic representations may be more likely to facilitate social learning and influence beliefs, perceptions, and attitudes (Giles, 2002). Rosaen & Dibble found that as children age, their favorite characters tend to be socially real and “stronger parasocial interactions were associated with more realistic characters” (Rosaen & Dibble, 2008, p. 153). Social realism refers to the likelihood that the events and people depicted in the show could happen in the real world (Rosaen & Dibble, 2008). Rosaen & Dibble (2008) defined social realism as the likelihood of a television show’s events and characters to happen in real life. To define a character as socially real, one must be able to imagine the character could live in reality without having to bend the rules of reality to include fantastic beasts (Rosaen & Dibble, 2008). For instance, a unicorn as a fantastical beast is not socially real, however, a person like J.J. in *Speechless* could really exist in real life. Additionally, realistic representations of real people and the option to reach out to these real people online is positively associated with parasocial interaction (Chung & Cho, 2014). Chung & Cho (2014), found the perception that reality television showcases real individuals motivates viewers to connect with characters through social media platforms, thereby strengthening their parasocial relationship (Chung & Cho, 2014). Reality television provides the ability for viewers to connect with their favorite characters in a way that fantasy television does not allow. The ability to connect with the cast from *BTW* not only through traditional viewing but also through social

media contact strengthens the parasocial relationship (Chung & Cho, 2014). We can hypothesize then that when a parasocial relationship is strengthened, the amount and reach of influence occurring in the relationship is also strengthened. Parasocial interaction combined with social media connection to real individuals with Down syndrome could function as exposure and thereby either increasing or decreasing the social distance between themselves and people with Down syndrome based on the messages contained in *BTW*.

### **Down Syndrome**

Approximately 1 in every 700 babies is born with Down syndrome (Parker, et al., 2010). Individuals with Down syndrome have an extra chromosome, causing both physical and mental changes (CDC, 2016). The flattened bridge of the nose is one of the most recognizable physical features of individuals with Down syndrome (CDC, 2016). Other common characteristics of those with Down syndrome are, “short stature, round face, almost-sharpened and up-slanting eyes” (Global Down Syndrome Foundation, 2017b). In addition, people with Down syndrome are often susceptible to many health problems such as immune diseases and heart defects (Global Down Syndrome Foundation, 2017b).

Since people with disabilities have been separated from the mainstream population, there are still many assumptions and stereotypes surrounding Down syndrome. The media has often depicted people with disabilities as piteous, burdens, villains, etc. These assumptions and stereotypical representations emphasize difference and with repeated exposure serve to prime viewers to associate complete difference, with people with disabilities, thus increasing the social distance between the majority public and those with disabilities (Baumann, 2007; Dixon & Maddox, 2005). Therefore, these depictions help perpetuate stigma of people with disabilities in society (Leavitt, et al., 2015; Milkie, 1999). While some research has been devoted to the

representation of people with disabilities in the media, there is a dearth of studies surrounding representations of Down syndrome specifically. This study fills a gap in communication literature by providing insight into the representations of people with Down syndrome in the media. The way *BTW* represents people with Down syndrome may have a positive or negative effect on individuals with this disability. If parasocial interaction can influence people to accept or change their attitudes about one stigmatized group, it is can be argued that this same phenomenon can exist in *BTW* and influence individual attitudes about Down syndrome. Before parasocial interaction and its impact can be fully understood, the messages *BTW* provides about individuals with Down syndrome must be assessed. Once this is better understood, the impact of parasocial interaction in *BTW* can be studied in context. Thus, to understand how *BTW* depicts individuals with Down syndrome, this study seeks to answer the question: What are the main messages and themes that surround *BTW*'s representation of Down syndrome?



## Chapter 2: Methodology

The way characters are portrayed in television shows allude to deeper societal and cultural messages (Kori-Butler, 2016). To begin to unearth these messages, content analysis was used to identify message constructs in context. Content analysis is a method often used in mass media communication research to analyze message construction (Lombard, Snyder-Duch, & Bracken, 2002; Macnamara, 2005). Content analysis was used to collect data from three seasons of *BTW*. The resulting data was analyzed and organized into themes through the process of thematic analysis.

### Content Analysis

Media message construction and prolonged exposure to stereotypical representations have the power to influence public perception (Dixon & Maddox, 2005). The unscripted nature of *BTW* allows people with Down syndrome to share their personal thoughts and feelings within different contexts. Content analysis can be used to understand how people with Down syndrome are represented in *BTW* and what messages this show provides the public (Krippendorff, 1989). Kori-Butler, (2016) describes content analysis of media messages in the following way: “Content analysis requires systematically watching or reading with an analytical and critical eye, going beyond what is presented and looking for deeper meanings and messages to which media consumers are exposed” (p. 2). These deeper meanings are uncovered by determining the quantity of message repetition and frequency (Macnamara, 2005, p. 4).

Content analysis has been used to analyze the impact of media messages in a variety of contexts. For example, to gain a better understanding of the representation of transgender individuals on television, Capuzza and Spencer (2017), used qualitative content analysis to analyze transgender characters from nine popular television shows. The study concluded that

though depictions of transgender individuals had improved, limitations in screen time, adherence to a heterosexual understanding of gender, and the politics surrounding transgendered individuals continued to limit the quality of transgender representations in the media (Capuzza & Spencer, 2017). Another research team used qualitative content analysis to determine how male nurses were being represented on television (Weaver, Ferguson, Wilbourn, & Salamonson, 2014). Their analysis revealed that many messages surrounding male nurses in television shows reinforced stereotypes (Weaver, et al., 2014). This result allowed Weaver, et al., (2014) to suggest practices for countering the impact of these stereotypes. Clearly, content analysis leads to an “understanding of social reality” (Cho & Lee, 2014, p. 17). Qualitative content analysis allows researchers to understand the underlying messages of a text, image, television show, or other media depiction and through careful analyzation determine probable audience reactions to the constructed message (Macnamara, 2005). Once the messages constructed in a television show are understood, then the impact of these messages can be researched further.

### **Inclusion/Exclusion Criteria**

The researcher analyzed season 1 (6 episodes) season 2 (11 episodes) and season 3 (10 episodes) of *BTW*. Each episode was approximately 40 minutes long, ranging from 41 minutes to 43 minutes. Full episodes were included in the analysis. A full episode is defined in this investigation as the scenes depicted between the introduction and closing of an episode. Data collection started after the words “previously” and ended right before “next time on *BTW*.” Unfortunately, the use of introductions for episodes was inconsistent, resulting in a lack of consistency in coding; as some scenes which may not have been part of an intro may have been excluded from data analysis. To establish coding consistency among episodes without clear

introductions or closings, scenes at the beginning of the episode that were structured as director prompted questions or interviews were not included in the final analysis.

### **Unit of Analysis**

A total of 26 regular episodes and one bonus episode, approximately 1,140 minutes or a little over 19 hours of episode footage were analyzed for content that constructed messages describing and representing Down syndrome. Each episode was viewed twice, once entirely without taking any notes (Roberts & Pettigrew, 2007). On the second viewing, the researcher took notes of how individuals with Down syndrome were represented, as well as scenes and quotes that invalidated or reinforced stereotypes associated with Down syndrome (Weaver, et al., 2014). Representative quotes were transcribed verbatim and added to the analysis (Weaver, et al., 2014). A compilation of Down syndrome stereotypes was used to inform the researcher of some of the common stereotypes associated with Down syndrome (See Appendix A). However, the written categories and stereotypes found in the show and included in the notes were not limited to the knowledge of these stereotypes. In addition, episode events, such as Rachel facing her fears (season one, episode five) and the Red Carpet Ball (season two episode one), were also noted for each episode. Often the researcher would rewind and pause the episode to ensure data was accurately captured. During the episode, notes were taken by hand and were then transferred to a Google document to prevent notes from being lost or misplaced. The notes for each episode included a brief description of the episode, notes about stereotypes, surprising scenes, and a list of episode events. The compilation of these notes totaled 44 pages of data for analysis.

### **Data Analysis**

In order to determine the main themes or messages of *BTW*, thematic coding was used to group common themes using Owen's (1984) framework. The 44 pages of data were examined; repeated



and recurring messages, situations, and concepts were identified and connected to create themes (Owen, 1984). The resulting themes were analyzed for similarities and grouped together to create four major themes. For each theme, representative quotes and examples from *BTW* are included to depict how the theme manifests in *BTW*. Many of these examples reference the names of specific individuals with Down syndrome and their families (See Appendix B for a compilation of names and familial connections).

### Chapter 3: Results

Media depictions of populations with whom the public has had limited or no exposure, serve as vicarious meetings (Leavitt et al., 2015; Schiappa, Gregg, & Hewes, 2006). Messages and themes that are used to define the nature of the media representation have the ability to create positive or negative messages and associations connected to a group of people (Dixon & Azocar, 2017; Schiappa, Gregg, & Hewes, 2006). The themes and messages surrounding *BTW*'s depiction of Down syndrome are relevant and significant to individuals connected with Down syndrome, as they could be the only exposure some viewers have to individuals with Down syndrome. The main themes depicted in *BTW* were identified based on repetition, show focus, and the researcher's knowledge of stereotypes and social and cultural norms. The data analysis revealed four major themes: Normalizing the Other, To Parents, Different Not Less, and Reality TV. Each major theme is accompanied by a number of subthemes. Each thematic category's subthemes are numbered in the following way: (1), (2), etc. If a subtheme has subthemes, these are denoted by the subtheme's number followed by a letter in alphabetical order. For example, if subtheme (1) has two subthemes these would be denoted by (1a) and (1b). Relevant quotes and scenes from *BTW* are used to define and showcase each theme below. Following each example are several letters and numbers. The letter 'S' and following number denotes the season and the shortened 'Ep.' And the second number denotes the episode. For example, (S1, Ep.1) refers to season one episode one. When a quote from an episode is utilized, the corresponding time stamp from the episode is added to the season, episode format, i.e (S1, Ep.6, 3:17-3:19). Although the above system is used for readability, please note that all quotes, summaries, and stories are from seasons 1, 2, and 3 of *BTW* (Korkoian, 2015-2017).

## **Normalizing the “Other”**

Normalizing the “Other” encompasses how *BTW* ignores past representations and stereotypes and instead presents people with Down syndrome as human beings with typical desires and goals. *BTW* focuses on the depictions of Down syndrome that reflect behaviors, desires, and experiences of the majority. The major theme ‘Normalizing the Other’ is broken down into seven sub-themes: (1) Multifaceted Human Being, (2) Emotions Galore, (3) Cultivate Familial Relationships, (4) Friendship, (5) Goals and Dreams, (6) Desire for Intimacy and (7) Conflict Resolution. Stigmatization of people with Down syndrome, based on their physical features has dehumanized this population and separated them from the rest of society (Goffman, 1963). *BTW* tries to put a face and reason behind the stereotypes and stigmas associated with Down syndrome. Instead of a faceless, voiceless silhouette, the audience is given blue eyed, red haired, Rachel with her many fears and quick laugh. Down syndrome is not the end all: it’s a beginning to a new story. These adults have familial relationships, friends, and romantic relationships. They are involved in classes and give back to the community by volunteering, creating art, and working various jobs.

### **(1) Multifaceted Human Beings.**

While people with Down syndrome and other disabilities are often represented as innocent or children in an adult’s body like Tom Hanks’ character in *Forest Gump*, individuals with Down syndrome in *BTW* have age appropriate desires that reflect adulthood (National Down Syndrome Society, 2015). For example, Sean and Steven share drinks at a bar, Rachel and Steven enjoy R-rated movies, John and Elena swear, and Megan is a self-professed party girl that wants to go clubbing for her birthday (S1, Ep.1, Ep.2; S2, Ep.1, Ep.2, Ep.8). The adults featured in *BTW* talk

about baseball, celebrity crushes, and play games together. Additionally, the adults in *BTW* are involved in improv, poetry, cooking, yoga, dance, and various other classes.

## **(2) Emotions Galore.**

People with Down syndrome are described as “always happy” and while people with Down syndrome may reflect happiness, they have the ability to experience other emotions (Global Down Syndrome Foundation, 2017a; National Down Syndrome Society, 2015). Below are several examples that depicted the wide range of emotions represented in *BTW*. Megan cries after meeting with her dad because she misses him (S2, Ep.6). Rachel is nervous about an upcoming camping trip. Elena is jealous about Angel and Cristina’s relationship (S2, Ep.8; S2, Ep.1). Sean is scared to move into the apartment by himself and Hiromi talks about how when Elena was little she always smiled (S2, Ep.5; S1, Ep.6).

## **(3) Cultivate Familial Relationships.**

The adults with Down syndrome featured in *BTW* have relationships with their parents and siblings. John and his family engage in teasing. John tells his family that the first place he is going to take his parents with his new driver’s permit is the “Nursing Home” (John, S2, Ep.2,6:19). Rachel roasts her dad at an event, Megan tries on her mom’s wedding dress, Cristina is shown chasing her dad with a towel and teasing her parents and siblings (S2, Ep.Bonus; S1, Ep.2).

## **(4) Friendship.**

The seven adults with Down syndrome featured on *BTW* experience friendship. While these adults are friends both in real life and on the show, they are also shown hanging out with other adults at Leaps and Bounds (an adult day center). Sean has a good friend named Sean C. who does not have Down syndrome. When Sean C. is thinking about popping the question to his

girlfriend he asks Sean for help picking out the ring and then asks for him to be his best man (S2, Ep.8). Megan is surprised by a friend from high school who does not have Down syndrome at a store and they shop the afternoon away together (S2, Ep.2).

#### **(5) Goals and Dreams.**

Each adult with Down syndrome featured on *BTW* has goals and dreams that they are working toward. Rachel works on conquering her many fears. Rachel's fear of loud noises and crowds has kept her from many fun experiences (S1, Ep.5). She gets invited to an Adam Lambert concert and overcomes her fear and is able to enjoy the experience (S1, Ep.5). Another episode shows Rachel conquering her fear of camping alone (S2, Ep.8). Ultimately, Rachel's goal is to be an actress, so she takes acting classes and gets connected with an agency (S3, Ep.3). John, on the other hand, wants to become a rapper and works with his school and friends to make that happen (S1, Ep.3). He writes a rap and performs it at an open mic night (S1, Ep.6). Megan has previously taken college classes and is interested in taking college classes while in California (S1, Ep.1, Ep.4). Cristina wants to be on *Dancing with the Stars* and starts to move toward that goal by dancing in a dance competition called the Emerald Ball (S2, Ep.3). To achieve her dream of becoming a poet, Elena is currently in a poetry class and performs at an open mic night (S2, Ep.8). Steven and Sean want to live alone which is a goal that is echoed among the adults (S1, Ep.1; Ep.5).

#### **(6) Desire for Intimacy.**

The very first episode starts off with Sean and Steven in a bar (S1, Ep.1). Over a few drinks, they ask a woman without Down syndrome at the bar if she has a boyfriend (S1, Ep.1). Unfortunately, she says she does and one conversation ends, while another begins (S1, Ep.1). The desire for a girlfriend or boyfriend, for connection and love, is a common theme in *BTW*. People with Down

syndrome desire to date, fall in love and get married. In fact, *BTW* spent a great deal of time on the love interests and narratives of the adults with Down syndrome. Sentiments of “I need a girlfriend” (Sean) or boyfriend were common themes reflected in longing from Rachel, Steven and Elena to be in relationships (S1, Ep.3, Ep.4, 28:02-28:03; S2, Ep.8). Steven’s need to have a girlfriend is reflected in the following statement: “I have no one. I’m desperate” (Steven, S2, Ep.1, 16:32-16:35). Adults with Down syndrome are shown to flirt with people who have disabilities and those who do not: “The teacher I like her. She is a babe” (Sean S1, Ep.6, 3:17-3:19), Cristina has a crush on her dance teacher and Steven tells Megan, “You do have pretty eyes” (Steven) (S1, Ep. 6; S2, Ep.4, Ep.8, 38:00-38:01). Some relationships like Angel and Cristina’s have morphed from dating to engagement. Not everyone has experienced dating at first, but the desire to date is strong among the adults with Down syndrome. Steven is attracted to people without a disability (S2, Ep.1). Steven has asked girls out before but has had little successes (S2, Ep.1). Without first-hand dating experience, Steven gains most of his knowledge about girls and dating from the movies he watches (S2, Ep.1). Steven wrote a dramatic scene for his drama class depicting how he tries to pick up girls without disabilities and how that tends to backfire (S2, Ep.1). In the scene, Steven reacts to a typical girl rejecting him, by saying the line “Prejudice against [sic] I have a disability, but it’s not my fault” (Steven, S2, Ep.1, 15:47-15:43). Later, Steven and his mom have the following conversation: “Yeah I’d like to date is uh somebody who’s a typical girl” (Steven). “And how’s that working out for you?” (Claudia). “Not that great” (Steven) (S2, Ep.1, 18:10-18:15). Steven’s parents encourage him to consider dating a girl who has a disability (S2, Ep.1). Rachel’s brother sets her up on a dating site for people with disabilities (S3, Ep.5). This push toward dating people with disabilities seems to be due to the belief that people without a disability may never see people with Down syndrome as a suitable

life partner. While this may be true based on current societal values, this push could also be due to parents not wanting their children to be hurt. The conversation surrounding dating someone like them, with Down syndrome, sounds eerily like “date your own kind.” This encouragement could be what pushed Steven to start pursuing Megan.

With a member of the cast getting engaged in the first season, marriage was constantly discussed. Many of the adults with Down syndrome mentioned that getting married or having a significant other was their dream. Rachel, Megan, and Sean express the desire to get married (S1, Ep.3; S3, Ep.7). When Cristina was born, her parents were sure the dream of walking their daughter down the aisle and seeing her married would never come true (S1, Ep.2). Even though Cristina and Angel dated for four and a half years before becoming engaged, their parents are involved with helping them set goals and prioritize independence (Angel, S1, Ep.6, 3:53). Despite parental involvement, Cristina and Angel recognized that they have trouble using effective communication strategies (S3, Ep.8). Therefore, they actively solicited advice from other couples and individuals about communication strategies for a healthy marriage (Se, Ep.8). One of the married couples Cristina and Angel talked to about communication, included an adult with Down syndrome (S3, Ep.8). *BTW* shows an adult with Down syndrome successfully married and Cristina and Angel, trying to prepare for marriage in every possible way.

#### **(7) Conflict Resolution.**

In the *BTW*, adults with Down syndrome solved their own conflicts, through talks and meditation. While there were times when another adult without Down syndrome would step in to help someone who was upset, most of the major conflicts were resolved by the adults with Down syndrome. One repeated response to feeling upset was leaving the group. At the bowling alley, Elena gets upset and leaves the group (S1, Ep.1). Cristina goes over, asks her what was wrong

and comforts her (S1, Ep.1). Once the problem is known, Elena discusses why she was upset with John and Cristina, then all is well (S1, Ep.1). Another example of conflict resolution occurs when Megan and a few other girls confront Sean about his infatuation and claim of dating the famous singer Meghan Trainor (S2, Ep.7). This confrontation results in Sean leaving the room (S2, Ep.7). When Elena sees that Sean is upset, she talks to him and then confronts Cristina and Megan by yelling that Sean was upset (S2, Ep.7). The situation escalates when Megan refuses to apologize, and Steven takes Megan's side instead of Sean's (S2, Ep.7). Finally, Elena calls the group into the kitchen to settle the dispute (S2, Ep.7). After this interaction, they are all able to talk it out and make peace (S2, Ep.7).

### **To Parents**

This theme is defined by parents shared experiences related to Down syndrome, i.e. the feelings that occurred when parents first found out their child had Down syndrome, as well as the parent experience of having a child with Down syndrome and the support network created by parents with Down syndrome for one another. The larger theme of 'To Parents' is broken into 2 sub-themes: (1) A Special Club and (2) Your Life Revolves Around Your Child, which discusses birth reaction experiences and support, and 'Your life revolves around your child' which looks into the experience of raising a child with Down syndrome.

#### **(1) "A Special Club" (Gary, S2, Ep. 4, 17:41-17:43).**

Throughout the seasons of *BTW*, parents shared narratives about the discovery that their child had Down syndrome. Most parents felt shocked and scared. This quote from Amy shows the general feeling of parental devastation "I don't think I ever prayed so hard that entire weekend. Like God please don't let my son have Down syndrome. I'm not ready for this, I can't handle this. This is too much" (Amy, S3, Ep.3, 15:42-15:52). Previous research has shown that the birth



of a child with Down syndrome is often met with negativity both from medical professionals and family and friends (Lalvani, 2011). *BTW* reinforces these findings as responses of family and friends were also characterized by negative reactions. For example: Rachel's mom Laurie shared that, "When Rachel was born, people reacted like someone died" (Laurie, S2, Ep.10, 2:50-2:55). The denial and negativity surrounding the initial diagnosis affirms how hard this news is to receive for some parents and their social networks. To mitigate this, Sandra put a message in their birth announcement, discussing that Sean has Down syndrome and they are excited to be a family and informed their friends and family how to react "Congratulate us, we're a family now. Please do not apologize, we're not sorry" (Sandra, S2, Ep.10, 3:18-3:22). This negative reaction of friends, doctors, and family points to an unfamiliarity and recognition that difference is stigmatized and therefore carries a negative connotation (Lalvani, 2011; Lalvani & Polvere, 2013). The fact that Sandra and the other parents of children with Down syndrome experienced negative reactions to the birth of their child with the disability points to a lack of knowledge and exposure to Down syndrome.

Abortion is something discussed often in the show, even the adults with Down syndrome understand that they could have been aborted. John tells the other adults that once the doctors knew John would have Down syndrome, they asked his mother if she wanted to terminate the pregnancy (S1, Ep.1). John's mother recalls that the doctors told her John would "never be a productive member of society" (S1, Ep.1). American culture and society informs people on how to react to differences and stereotypes influence our understandings of the ability of a stigmatized group. Similarly, the impact of Japanese culture is seen in the show. Elena's mother is Japanese, and Elena was born in Japan. While sentiments are changing, the Japanese culture is still impacted by past stigma and shame associated with people who are considered disabled or

different and their families (Heyer, 2015). Being accepted and part of a group is central to the Japanese culture, therefore being stigmatized or outcasted is unthinkable (Kayama & Haight, 2011; Markus & Kitayama, 1991). Elena's mother echoes these sentiments and mentions feelings of shame and the struggle to accept her daughter (S1, Ep.1, 3; S2 Ep.4).

Once the parents became more informed and got to know their children with Down syndrome, their perspectives changed. For instance, in one scene Cristina and her mom look at baby pictures and Cristina's mother shares her concern, worry, and sadness that she felt when the doctor informed her that her baby had Down syndrome (S1, Ep.6). The lack of information provided to Cristina's parents about Down syndrome increased their fear and worry (S1, Ep.6). In hindsight, Cristina's mother wishes that someone would have told her that Cristina would grow happy and healthy and always make her laugh (S1, Ep.6).

Due to the lack of positive medical information, parents of children with Down syndrome featured on BTW saw other parents as invaluable resources for advice, advocacy, and support (Lalvani, 2011). When Megan goes to speak in Trinidad, the moms are asked to share their experiences, and the parents at the conference were able to ask questions (S2, Ep.4). Another scene showed the parents of adults with Down syndrome talking to parents of younger children with Down syndrome (S2, Ep.10). In fact, Sandra states, "You know, I would not have survived without the mentors that we had, 'cause this was never in the parenting handbook" (Sandra, S3, Ep.8, 5:46-5:52). Kris echoes this sentiment, "The most I ever learned was from other parents." (Kris, S3, Ep.4, 29:14-29:17). The tight-knit community is bound and formed because of connection to people with Down syndrome. Amy thanks everyone at her baby shower by saying, "I'm so fortunate, like 'cause if we didn't have Rocco, we definitely wouldn't be part of this like incredible community" (Amy, S3, Ep.10, 21:37-21:42). Hiromi mentions that having a child with

Down syndrome is difficult (S2, Ep.4). Laurie took time to chat with Hiromi and let her know she is not alone (S2, Ep.4). Beatriz and Laurie give advice to Amy and encourage her with stories of how their child with Down syndrome reacted to a new baby in the house (S3, Ep.10). Additionally, the adults with Down syndrome are also present to provide new parents of children with Down syndrome hope in the midst of negative information. In one of the episodes, the adults with Down syndrome wrote letters to new parents of babies with Down syndrome. The following is an excerpt from the letters: “Dear new moms or dads your son or daughter can achieve anything” (Megan). “Your child w-will [sic] do great things (John). “Your baby can be whatever they want to be” (Elena). “You can teach them how to crawl, read, laugh. Laughter is the most important thing” (Rachel). “I know it is hard for your child to do some things” (Cristina), (S2, Ep.10, 39:01-39:33). While this is only part of the letters, the message is clear: a child with Down syndrome can have a quality life. The adults wrote these letters to show new parents of kids with Down syndrome that quality of life is possible with Down syndrome. The repetition of the need for connection, understanding and mentoring parent to parent, indicated that support was an important part of allowing parents to accept their children with Down syndrome and begin to advocate for them.

## **(2) Your Life Revolves Around your Child.**

Parents of children with Down syndrome are worried about providing the best care, opportunities, education, and growth for their child (Baker, 2014). They want their children to be safe, independent, financially stable, and engage in meaningful relationships (Baker, 2014). Discussions about death and the capability and care of their adult with Down syndrome caused worry and reinforced the need for autonomy (Baker, 2014; S1, Ep.4). The stigma associated with Down syndrome is often a barrier to reaching these parental goals (Barker, 2014). Society

applies the label “Down syndrome” and right away limits the abilities of a baby with Down syndrome (Lalvani, 2011). Claudia mentions that when someone is labeled with a disability, that disability becomes the focus and any ability an individual may have is lost (S1, Ep.1). Steven echoes this sentiment, “We have this disability. It doesn’t define who we are but sometimes people limit us on, like, uh what is acceptable in society” (Steven, S2, Ep.Bonus, 4:07-4:17). Due to society’s limited and stigmatized view of Down syndrome, parents who want their children to have a mainstream, public school education, must fight to achieve an education balance that meets both parent’s expectations, the individual with Down syndrome’s needs, and the school’s ability and willingness to accommodate (Lalvani, 2011; S3, Ep.8). Early intervention programs provide children with Down syndrome aid in the development of verbal and motor skills and thus are one way parents of children with Down syndrome strive to give their child a “fighting chance” (S3, Ep.3). Raising a child and teaching an adult who had Down syndrome is a hands-on, 24-hour job. All the adults with Down syndrome in *BTW* are unable to drive and therefore are driven around by their parents to every event, work day and date. When Megan and Brendan are on a date, the moms are at a nearby coffee shop waiting for Megan and Brendan to finish their date. Claudia points out that parents are very involved with their child who has disabilities, which makes letting go harder (S2, Ep.5). The parents are actively involved in helping their child reach their dreams and goals. Commitment to goals caused Kris to move from Colorado to California to help Megan reach her dreams (S2, Ep.6). John’s mother paid for his album covers under the assumption John will pay her back (S2, Ep.2). Because of all this close involvement, the difficulty of letting go is often discussed: “Your priority for so many years out of necessity is taking care of your child” (Kris, S3, Ep.4, 30:58-31:03). This increased worry is not something attributed to typical children, but specifically for the child or adult with Down syndrome or other

disability: Both Angel's grandparents and Cristina's parents are worried about their relationship. Angel's grandmother and Cristina's mother have the following conversation: "We want them to grow up and be independent but they're our babies" (Angel's grandmother, 35:37-35:39). "Do you have the same feelings with the other kids" (Beatriz) "No." Letting go of kids with disabilities seems to be harder than letting go "regular kids" (Angel's grandmother, S2, Ep.6, 35:37-35:39).

### **"Different, Not Less" (Ferguson, Saines, & Jackson, 2010).**

This quote from *Temple Grandin* represents the way *BTW* depicts the difference of individuals with Down syndrome. The representation of Down syndrome in *BTW* way is not idealistic. *BTW* spends time creating a picture of adults with Down syndrome as 'normal' but does not hide their differences. The adults with Down syndrome in *BTW* are shown to get upset, reacting impulsively, and misunderstand abstract concepts. "Different, Not Less" encompasses two subthemes: (1) Facilitated Independence, is Independence, and (2) Cognitive Functioning. These subthemes include their own subthemes. For instance, Facilitated Independence, is Independence is further categorized into three subthemes: (1a) Facilitating Independence in Living Alone (1b) Facilitating Independent Relationships by Ensuring Knowledge of Household Tasks and (1c) Facilitating Independence in the Workforce. Similarly, Cognitive functioning is also broken in two subthemes: (2a) Abstract vs. Concrete Thinking and (2b) Inappropriate Displays of Affection.

#### **(1) Facilitated Independence, is Independence.**

This theme encompasses depictions of independence as a facilitated step by step process and is further broken into 3 minor themes, (1a) facilitating independence, (1b) in living alone, in relationships, and (1c) in the workforce. A common stereotype postulates that adults with Down

syndrome are unable to be self-sufficient or to live independently and are unable to obtain and keep a job and thus unable to contribute or be an active member in society (Global Down Syndrome Foundation, 2017a; National Down Syndrome Society, 2015). This stereotype seems to be derived from the non-disabled version of independence, while *BTW* functions on another definition of independence. Instead of independent and dependent being defined as distinct areas individuals exist within, *BTW* depicts being independent as a spectrum. In *BTW*, the question is not “Can individuals with Down syndrome be independent?” but rather, “What level of independence can individuals with Down syndrome navigate successfully?” Independence occurs gradually, from independent living classes, trial periods, and activities at the adult day center, these opportunities allow the adults with Down syndrome safe places to learn and make mistakes. Guidance and assistance only when necessary allows people with Down syndrome to live autonomously (Baker, 2014). Instead of an impossibility, this show frames independence as a learned possibility. The new perspective of independence provides insight into the public’s limited sense of the word and expands the capability that people with Down syndrome possess. This step by step progress toward independence is similar to a child learning to ride their bike without training wheels. Parents do not simply pull off these training wheels and expect their child to be as good at riding a bike as before. Instead, parents prepare their children, they get them familiar with the bike, how to get on, what pedaling feels like, and then they take the training wheels off. The first time a child gets on the bike, parents hold on to them and help them get their balance, later when the training wheels come off parents celebrate the milestone. Children usually fall several times before succeeding with the new bike. Instead of scolding, parents often scoop kids up, give them hugs, bandage skinned knees and support their children as

they try again. This example perfectly mirrors the way *BTW* depicts parents of adults with Down syndrome facilitating their child's independence.

***(1a) Facilitating Independence in Living Alone.***

Both parents and their children considered moving out and learning to function independently as the ultimate goal (Baker, 2014). For instance, Steven wants to be independent but is concerned with how his parents will react (S2, Ep.4). He worries about living alone with a disability (S2, Ep.4). Megan dreams of living in L.A. by herself without her mom (S1, Ep.1). Sean receives his Department of Housing and Urban Development (HUD) voucher which provides him with the financial assistance he needs to live alone (S2, Ep.4; U.S. Department of Housing and Urban Development, n.d.). While it is easy to make statements about desiring independence, the process from dependence to independence is made possible through facilitation. Due to Sean's receiving the HUD voucher, he will need to move into a new place in four months (S2, Ep.4). Steven and Sean's parents discuss the possibility of Steven and Sean living together at an air bed and breakfast rental (Airbnb) to experience living independently in a controlled environment (S2, Ep.5). Airbnb's are often used as vacation homes and would allow Sean and Steven's parents to rent out several months at a time for this independent living trial run. The parents will not always be around and living alone is the first step to making sure their adult children can function without them (S2, Ep.5). This opportunity to experience living alone on a trial basis familiarizes the adults with Down syndrome with what living alone really means. Robert, a supported services member, checks on Sean and Steven to facilitate independent living. Supported living services allows people with disabilities to live independently and reach their goals by providing support tailored to the individual needs of a person with a disability (State of California, Department of Developmental Services, 2018). Supported living services help adults with

developmental disabilities in a variety of different ways, from choosing an apartment to daily activities and even finances (State of California, Department of Developmental Services, 2018). Robert describes his role as a facilitator in the following way, “We’re not here to do things for you, but we’re here to do things with you” (Robert, S2, Ep.5, 39:15-39:20). Sean asks the specialist to do things for him, but the specialist kept saying “Oh I want to see you do it” which further enforces the point of facilitating not enabling (Robert, S2, Ep.5, 40:07). Cristina gets the opportunity to move out of her house into an apartment (S3, Ep.1). After looking at accommodations with her parents, Cristina independently chose which apartment she would live in (S3, Ep.9). Although Cristina was both excited and scared about having her own apartment, she seems content and happy in her new space (S3, Ep.9).

***(1b) Facilitating Independent Relationships by ensuring knowledge of household tasks.***

Special care is taken to ensure Angel and Cristina will be able to live independently. While many of the adults with Down syndrome featured on *BTW* are capable of fixing some meals by themselves, the teaching of household chores (cleaning, cooking, managing money etc.) can be difficult for adults with Down syndrome to learn (S2, Ep.Bonus). Hence, Angel and Cristina take independent living classes (S2, Ep.6). Together, they learn about how to do laundry, count and spend within their budget, and how to read and follow directions to get from one place to another (S2, Ep.6). For example, a living coach goes with Angel and Cristina to the laundromat and the living coach is simply there to help if needed (S3, Ep.8).

***(1c) Facilitating Independence in the Workforce.***

Many of the adults with Down syndrome featured in *BTW* have jobs or got jobs during the course of the show. Sean works at Home Depot with a support person, with the goal of working completely independent when he is ready (S2, Ep.4). The transition from one job to another can



be complicated. With a plethora of new faces and tasks to learn, people with Down syndrome can become overwhelmed. When Steven gets a job at an office, he is supported by a job coach, who helps both Steven and the company to become confident in Steven's abilities (S3, Ep.5). An employment consultant met with Megan before her interview, offering advice about best interview practices, such as eye contact (S2, Ep.5). During the interview, Megan answered all the questions and the employment consultant stayed in the room during the interview for support (S2, Ep.5). To become a barista, Elena has an independent interview with the coffee company and then is trained on the job by a manager (S3, Ep.4). During Elena's trial period, all her shifts are conducted under the watchful eye of the manager (S3, Ep.4). Before Elena is offered a regular shift, Elena's manager gives her an evaluation on a whiteboard (S3, Ep.8). Elena is able to evaluate herself and then compare the manager's evaluation with her self-evaluation (S3, Ep.8). This hands-on assessment allows Elena to assess and accept her job performance and to clearly identify the areas of growth. Facilitation and guidance in the beginning of a job often results in an independent work environment for the adult with Down syndrome. For instance, Rachel works at Scottish American Insurance as a mailroom assistant and mails paychecks and policies (S1, Ep.5). Rachel had a job coach when she first started at the company but no longer needs to extra help (S2, Ep.7).

Every adult with Down syndrome has different abilities and is in need of different support to become independent. As independence is learned, mistakes are made. For instance, Sean had trouble opening a can with a can opener, Steven forgot to pack pants when he moved into the trial house with Sean, and Cristina and Angel forgot some of the sheets they were washing in the washer (S2, Ep.5 & Ep.Bonus). Repetition, classes, and facilitation can result in

independence. After experiencing and practicing what they need to do, adults with Down syndrome can often perform tasks independently without a facilitator.

### **(1) Cognitive Functioning.**

Cognitive Functioning includes the behaviors and statements that depict cognitive functioning capabilities that differ from the cognitive capabilities of people without Down syndrome and is broken down into two sub-themes: (2a) Abstract vs. Concrete Thinking and (2b) Inappropriate Displays of Affection.

#### ***(2a) Abstract vs. Concrete Thinking.***

In *BTW* abstract knowledge and its subsequent understanding is tied to the concrete action of the adults with Down syndrome experiencing the concept. For instance, Sandra mentions that Sean does not understand abstract concepts easily and that they need to be made concrete so that he can really understand the concept (S2, Ep.5). When Sean and Steven stay at the bed and breakfast for a trial of living independently, they are receiving a concrete experience of what living independently looks like and thus are better equipped to move out by themselves later (S2, Ep.5). Another example of this theme occurs when Kris tries to tell Megan that having a baby is difficult (S1, Ep.3). Megan steadfastly holds onto her dream of being a mom and does not believe it will be hard to take care of a baby (S1, Ep.3). Therefore, to show Megan how much work a baby is, her mom orders a training baby (S2, Ep.10). This fake training baby cries, needs to be changed, and fed, and acts similarly to a newborn (S2, Ep.10). Megan names the baby Audrey Elizabeth and says, “I can’t wait to be a mommy someday” (Megan, S2, Ep.10, 14:01-14:03). This excitement turns to frustration as the training baby repeatedly screams (S2, Ep.10). At the end of this experience, reality sets in and Megan decides that “Being a mom is really hard and frustrating” (Megan, S2, Ep.10, 15:07-15:11). Even so, Megan wants to take mommy classes

to prepare for having a baby in the future (Megan, S2, Ep.10). The concept of having a baby was picturesque in Megan's understanding, once she had the experience, she understood that taking care of a baby can be an arduous process.

In some areas of life, changing an abstract concept to a concrete experience is not always encouraged. The limitation of concept experience to conversation, not action results in a convoluted understanding of certain topics. During the show, the adults have the opportunity to sit through a class on sex (S3, Ep.7). Many of the adults with Down syndrome exhibited signs of nervousness and fear in the aftermath of the sex class (S3, Ep.7). Due to the difficulty, the adults with Down syndrome featured in *BTW* exhibited to understanding abstract thinking, topics like sex are difficult to decipher, even when the concepts are repeatedly taught. For instance, Cristina and her dad discuss the sex class she took (S3, Ep.1). She tells her dad it was the first time she learned how to put a condom on (S3, Ep.1). Mariano asks her if she has had sex and Cristina says that she has (S3, Ep. 1). This conversation follows her confession: "What is having sex" (Dad)? "That part I'm not sure yet" (Cristina) 9:04-9:08 "But you told me you had sex. You never took your clothes off" (Dad)? "No, I never do that" (Cristina), (S3, Ep.1, 9:00-9:10). Although Cristina has attended a class on sex and has been provided conceptual knowledge, sex is not concrete due to lack of experience, thus Cristina was still unsure about what sex was exactly.

***(2b) Inappropriate Displays of Affection. (McGuire & Chicoine, 2002).***

Concrete understanding revolving around relationships and their progressive steps were also depicted as a difficult concept for the adults with Down syndrome featured in *BTW* to understand. One common occurrence among these adults was an impulsive commitment, especially in romantic settings. This quick 'falling in love' and wanting to move past friends to commitment all at once, points to a lack of understanding of the flow of events or steps from one

stage to another. For instance, on the first date, Sean calls his blind date sexy (S2, Ep.3). They both say I love you and discuss marriage (S2, Ep.3). Similarly, Cristina's crush on her dance teacher prompts her to write him a letter telling him how she feels and asking about his relationship status (S2, Ep.4). Additionally, Sean hits on Hillary and Megan even though both have boyfriends (S1, Ep.4). Upon confrontation about his lack of boundary management, Sean becomes upset (S1, Ep.4). Furthermore, Megan is warned by her mother not to talk about marriage or ex-boyfriends on her first date with Steven (S3, Ep.2). The tendency to go fast in a relationship is reflected in the repeated advice of parents and other adults with Down syndrome to take things slow (S3, Ep.10). This advice is given on a continuous basis, implying impulsiveness is the tendency of many adults with Down syndrome.

### **Reality TV**

This theme encompasses how the medium of reality television influences the representations depicted and the audience perception of those representations. The more real the depictions in a reality TV show are perceived to be the greater the influence the show's representations have on the viewer (Busselle & Greenberg, 2000). Reality TV is broken into two subthemes: (1) Change in Season Narrative and (2) In Reality, it is Reality TV. The Change in Season Narrative discusses the difference in focus from the first season to the second and third seasons. In Reality, it is Reality TV encompasses the actions and excursions that do not reflect the reality of most individuals, especially those with Down syndrome.

#### **(1) Change in Season Narrative.**

While there are many positive aspects to the representation of *BTW*, it is clear that a season to season narrative shift exists. The first season is focused on humanizing the other, creating a look into the lives of adults with Down syndrome. The second and third season continues this theme

with some notable changes. First, the parents of the adults with Down syndrome are interviewed more and start having a more prominent role in the show and second, the relationship between Megan and Steven take a prominent role in the narrative.

Season one is focused on the adults with Down syndrome specifically. The parents and families of the adults with Down syndrome are included in the interview process, but less time is spent on building the parent support and parent experience narrative. Additionally, in season three, a new couple, Amy and Chris, and their 2-year-old son Rocco are introduced (S3, Ep.3). *BTW* follows the struggles of Rocco's parents as they try to provide him with every opportunity from early intervention programs to educational Individualized Education Plans (IEP) (S3, Ep.3; Ep.8).

The end of season two and the whole of season three is saturated with one relationship. Two of the adults with Down syndrome, Megan, and Steven, are interested in one another and eventually start to date. When Steven reveals that he is interested in Megan, the cast interview time begins to skew in Steven's favor, resulting in many face-to-face interviews about Megan (S2, Ep.9; S3, Ep.1). In Season 3 *BTW* adds special effects to show Megan and Steven's text messages on the screen. (S3, Ep. 2). "Hi Steven. What is up? I had so much fun last night :)" (Megan) and "Me too :) :) :)" (Steven) (S3, Ep.2, 1:28-1:35). In the previous episode, under a sky filled with fireworks, Steven asked Megan on a date, this is the "night" Megan is referring to in her text message (S3, Ep.1). Although the text bubbles only appear in episode one of season three, the addition of special effects creates a fictional effect. Later in the season, Megan and Steven's previous dates and intimate moments are replayed on screen, also adding to the fictional effect. Steven and Megan's drama after breaking up is also featured in the spotlight. Megan chooses outfits that she thinks will make Steven jealous (S3, Ep.7, Ep.9, Ep.10). When Steven

brings his date Lauren Potter to a party at Rachel's house, Megan introduces herself as Steven's ex-girlfriend (S3, Ep.10). Lauren, Steven's date asks about Megan: "Do you know her?" (Lauren) "Uh no. Uh, she's one of the cast" (Steven) (S3, Ep.10, 26:36-26:41). Everything Megan does at the party is her attempt to make Lauren and Steven jealous.

## **(2) In Reality, it is Reality TV.**

To be included in *BTW*, the chosen individuals with Down syndrome had to go through a screening process. The audition tapes included in the bonus episode, showed the adults with Down syndrome cooking on their own, talking about themselves, and speaking in a second language (S2, Ep.Bonus). Many of these individuals live in California and have access to programs and disability advocates. Unfortunately, the conditions and resources shown in the show are not available everywhere. *BTW* makes it look easy to find a day center and connect an adult with Down syndrome with peers, but unfortunately, this is not always the case.

Additionally, the trips, such as the girls trip to Trinidad and the whole cast cruise, are not a reality for many families (S2, Ep.3; S3, Ep.2). The adults with Down syndrome start having opportunities that, one could argue, exist due to their role in the show. John is a rapper and people who watch the show want him to succeed, as a result, they buy his songs on iTunes and want to buy his album and he is called by a recording studio in Georgia and asked to record in their studio (S2, Ep.9). Megan's mom mentions that "Megology (Megan's clothing business) literally exploded overnight" (Kris, S2, Ep.1, 13:42-13:45). While the representations of adults with Down syndrome carry unrealistic aspects, the presence of real people and lack of script alludes to the underlying reality in *BTW* (Hall, 2006).



## Chapter 4: Discussion

The vast majority of representations of people with disabilities in real life situations are still framed through a stereotypical lens. The stereotypical representational themes of: villain, super cripp, abnormal sexuality/asexual, monster, pitiful, maladjusted, worthless, burdensome and confinement discussed in the literature review reinforce the stigmatized status of disabilities by focusing on the negative differences supposedly created by the presence of a disability (Harnett, 2000). Stereotypical representations, such as pity, reinforce the differences between the majority ‘typical’ population and those with Down syndrome or disabilities in general (Hayes & Black, 2003). Even when a film or TV show represents disabilities positively, the lack of actors with a disability in the representation discredits the positive message of the depiction and instead reinforces that people with disabilities are not capable of acting, let alone controlling their public narrative. *BTW* joins the 5% of television shows and movies that use people with disabilities in roles that have a disability (Woodburn & Kopic, 2016). *BTW* allows people with Down syndrome to take back their narrative. Down syndrome is not represented as something you have that limits your abilities and your quality of life, it is something that you can “sparkle with.” (Megan, S1, Ep.6, 28:36-28:41).

### **Taking Back the Narrative**

As seen in the theme ‘Humanizing the Other’ and its concurrent subthemes, adults with Down syndrome in *BTW* are shown living everyday lives that in many ways mirror the lives of viewers. The adults in *BTW* go to work, have a relationship with their family, want to date, go on dates, desire to get married, get married, go to college, pursue careers, have goals and hang out with friends. The adults with Down syndrome in *BTW* are depicted as sexual individuals capable of having sex. Rarely does a media representation of a person with a disability display the person



with a disability as a person first and their disability second (Harnett, 2000; Hayes & Black, 2003). This depiction of ‘normalcy,’ the representation of a reality that does not differ drastically from “normal” life, can allow viewers to see similarities between themselves and people with Down syndrome. Stigma dehumanizes the other, *BTW* is rehumanizing adults with Down syndrome and showing the public that disability does not reduce one’s humanity or value (Goffman, 1963). However, *BTW* does not ignore the differences between the adults in *BTW* and the viewers. Society often fears people with disabilities due to fear of the unknown, *BTW* reveals the unknown and allows the differences associated with Down syndrome to be represented (Cervantez Thompson, Emrich, & Moore, 2003). The major theme of “Different not less” and the subthemes included in this theme reflect the differences between the viewers and the adults with Down syndrome featured in *BTW*. The cognitive functioning of adults with Down syndrome is represented for viewers as different. The struggle to understand abstract concepts, such as sex, does not become more important than the adults with Down syndrome themselves, rather it serves to depict their realistic cognitive functioning processes (Michlmayr, n.d.). Although confusion surrounds sex, the fact that sex is discussed in *BTW* and that people with Down syndrome are seen as sexual beings, breaks the past representational norms of asexual or abnormal sexual behaviors (Anderson & Kitchin, 2000). While everyone with Down syndrome functions at a different level, the concrete vs. abstract confusion and the “inappropriate displays” theme depict real challenges that some people with Down syndrome face (Michlmayr, n.d.; McGuire & Chicoine, 2002). Media representations create a semblance of ultimate dependence where people with disabilities must rely on people without disabilities for care, to accept having a disability, to function etc. (Barnes, 1992; Black & Pretes, 2007; Toutellotte, 2015). The adults with Down syndrome in *BTW* are not depicted as super crips who gain their independence by

overcoming their disability nor as burdens or worthless individuals who are unable to be independent and contribute to the community (Harnett, 2000; Longmore, 2003; Safran, 1998). On the contrary, adults with Down syndrome in *BTW* are depicted as individuals who are capable of gaining independence through facilitation. The representation of independence in *BTW* is refuting stereotypes and redefining independence capabilities of people with Down syndrome in the eyes of the public.

### **Implications for Viewers**

#### **Exposure.**

Due to the perception of different or ‘otherness’ associated with Down syndrome, the social distance between the public and people with Down syndrome increases (Baumann, 2007). Therefore, the lack of interaction between people with Down syndrome and the general public results in a lack of knowledge surrounding the ability and experience of having Down syndrome. *BTW* allows the public to vicariously peek into the lives of people with Down syndrome and be exposed to a world many have never been a part of in “real” life (Leavitt et al., 2015; Schiappa, Gregg, & Hewes, 2006). Over time, watching *BTW* frequently could result in the shortening of social distance due to parasocial interaction (Oullette-Kuntz, et al., 2010; Schiappa, Gregg, & Hewes, 2006). The majority of the public do not have deep connections or meaningful interactions with people who have disabilities (Taylor, 2017). Parasocial interaction can act as an interpersonal connection that can create a semblance of knowing the other, thus creating a moment of mediated connection to a member of a stigmatized group (Giles, 2002; Schiappa, Gregg, & Hewes, 2006). Negative stigma associations could be broken due to the presence of parasocial interaction and the dissemination of stereotypical misinformation about individuals with Down syndrome.

## **Education.**

The humanistic representation of people with Down syndrome in *BTW* facilitates a vicarious meeting which provides the viewer with information about a minority group with disabilities, providing both education and exposure (Leavitt et al., 2015). Similarly, to how *Little People, Big World's* positive representation of people with dwarfism served to educate the public about the 'reality' of living with dwarfism, the results indicate that *BTW* positive representation serves to educate the public about people with Down syndrome (Hayes & Black, 2003; Humphries, 2011). Additionally, since Humphries (2011), found that the representations in *Little People Big World* had a positive impact on those with dwarfism as well as those without disabilities, it is fair to conclude that the positive, humanistic, ability driven representation of people with Down syndrome in *BTW* may also impact those with Down syndrome in a positive way. The representations that we see in the media help inform the public about groups in society (Leavitt, et al., 2015). While sitcoms and family dramas add positive representations of disability, realistic depictions of individuals with Down syndrome in everyday life are likely to increase opportunities for social learning and ultimately influence beliefs, perceptions, and attitudes (Giles, 2002; Tsay-Vogel & Schwartz, 2014).

## **Implications for Parents**

While the public may be exposed to positive or negative stories about individuals with Down syndrome, the public may not have been exposed the devastating side of a Down syndrome diagnosis, as seen in *BTW*, turn into a positive understanding and love of a child or adult with Down syndrome. This "sense-making" process is important for people with children who have disabilities and those who do not to see and understand. Without showing this process in the media, members of the public who have not had contact with this group of people may have

unrealistic or stigmatized ideas about the reactions and subsequent long-term attitudes parents of children with Down syndrome feel toward their children (Leavitt et al., 2015). The public is given a glimpse into the journey that parents of children with Down syndrome have faced and can begin to understand the uphill battle these parents face as they garner resources and fight for acceptance for their child with Down syndrome (Baker, 2014).

While information about other conditions, such as cancer, have doctors specifically trained in the field of Oncology and experts about particular facets of the condition, Down syndrome is lacking a branch of medical study that is specifically devoted to specialization in Down syndrome (S2, Ep.10). In *BTW*, doctors and medical professionals are framed as providing negative messages that limit people with Down syndrome (S1, Ep.1). This one-sided rhetoric surrounding Down syndrome which focuses on the negative side of disability serves to further stigmatized notions of the inherent lack of value seen in the life of a person with Down syndrome (Lalvani, 2011; Lalvani & Polvere, 2013). The individual labeled as stigmatized or “different” is thought of as less valued, less of a person than a “typical” person (Goffman, 1963). Thus, instead of seeking the opinion of medical professionals who may lack specialized knowledge that comes from direct experience with children and adults with Down syndrome, parents of children with Down syndrome have specialized knowledge about their particular child and thus become the key to knowledge (S2, Ep.10). Not only is knowledge cultivated, but support is available. *BTW* creates a picture of parents fighting to flip stigma upside down and give their child the inclusive, acceptance they deserve (Baker, 2014).

### **Parasocial Interaction and Social Support.**

According to Krueter, et al., (2007) “People develop relationships with characters in literature, stories, news, and other ongoing vicarious mediated experiences, even when the characters are

fictional” (p. 226). Parasocial interaction allows viewers to create an interpersonal connection with individuals in the media, and Kreuter, et al., (2007) hypothesized that parasocial interaction can provide the benefits of social support, vicariously. Mattson and Hall (2011) defined social support as, “a transactional communicative process, including verbal and/or nonverbal communication, that aims to improve an individual’s feeling of coping, competence, belonging, and/or esteem” (p. 184). People seek social support from others who share similar experiences (Makabe & Hull, 2000; Simich, Beiser, & Mawani, 2003). Taylor (2011) discusses three kinds of social support: Informational, Instrumental and Emotional. Informational social support provides situation-specific information, resources, and strategies to help guide an individual through a stressful situation successfully (Taylor, 2011). Instrumental support consists of providing specific tangible aid, such as bringing a new mother meal, or paying for someone’s rent (Taylor, 2011). Emotional support consists of listening and validating an individual’s feelings, worries, stresses, and reminding them they are cared about by someone (Taylor, 2011). Emotional support is focused on trying to improve a person’s mood (Mattson & Hall, 2011). Mattson and Hall (2011), added two other kinds of social support, Esteem, and Network Support. Esteem support is a subcategory of emotional support and consists of messages that encourage an individual that they can handle the stress that is occurring in their life. Network support manifests in communication that reminds an individual they are not alone in facing the stresses of their lives and that they have a support network ready to help them (Mattson & Hall, 2011). Additionally, social support can also meet a need when a person perceives that they have access to social support (Taylor, 2011). Moreover, the narratives of others that one can identify with can serve to relate informational, and network social support (Kreuter, et al., 2007; Mattson & Hall, 2011). Parents of children with Down syndrome can relate to the struggles, successes, and reality of

living with a child or adult who has Down syndrome. Therefore, it is reasonable to assume that *BTW*, with its discussions of advocacy and parent support, is vicariously offering informational, emotional, esteem, and network social support to parents of children with Down syndrome (Kreuter, et al., 2007). If indeed parasocial interaction is present and *BTW* is acting as vicarious social support for parents of children with Down syndrome, then the individuals and situations represented in *BTW* could be providing these parents with hope, coping strategies, and an understanding of what is actually possible (Hogan, Linden, & Najarian, 2001). In a world that is constantly limiting and stigmatizing people with Down syndrome, *BTW* could be providing parents of children with Down syndrome, especially those who feel isolated by family and friends or have a young child with Down syndrome a needed support system, an acknowledgement that their child is not as limited as society would have them believe.

### **Reality Television**

Reality television shows attract viewers based on novelty (Hall, 2006). Similar to the draw of freak shows in history, the use of individuals with disabilities in reality television draws viewers based on their perceived abnormality or difference (Backstrom, 2012). *BTW* uses the “difference” or “otherness” of Down syndrome coupled with the novel approach of using seven adults with Down syndrome as the main characters to draw viewers in and gain their interest (Backstrom, 2012; Hall, 2006). While this novelty may have drawn viewers to watch season one of *BTW*, the novelty of seeing adults with Down syndrome on television may have waned by season two. The hyper-focus placed on Megan and Steven’s relationship near the end of season two, and throughout season three, could be the director and producers of *BTW* way of attempting to inject new novelty into the representation of *BTW*. If the show’s main purpose was to provide a look into what life is like with Down syndrome, then it has shifted to encompass more parent

interviews and screen time. The various trips, opportunities, and successes depicted in *BTW* are not the reality of everyone who has Down syndrome. Reality television is well known for showcasing lives of people that do not reflect the majority, such as *Kate Plus Eight*, a show about a woman who had eight children at once, and this theme is repeated in *BTW* as well (Hall, 2006). Viewers may expect a reality television show to reflect real life but acknowledge that editing and cutting can create an unrealistic representation of events (Biressi & Nunn, 2005; Hall, 2006). Disability and Down syndrome organizations such as Respectability, Global Down Syndrome Foundation and the Down Syndrome Association of Orange County have played either a consulting role or appeared in the show (Mizrahi, 2015; S2, Ep.2; S1, Ep.5). With the backing of organizations that advocate for disability rights, one can assume that these depictions of adults with Down syndrome are realistic; however, without viewer feedback, we only have one side of the story. While the presence of agencies and other families of children with Down syndrome and the presence of seven adults with Down syndrome point to the presence of real life depictions, the text message bubbles and replay of Megan and Steven's relationship highlights in season three does negatively impact the realistic nature of the show.

*BTW*'s representation of real people with Down syndrome, as 'normal' individuals with jobs, dreams, and relationships is a departure from previous depictions and thus, challenges stereotypical representations. In *BTW*, the people with Down syndrome are represented as humans first and then as individuals with Down syndrome. The way people with Down syndrome are depicted in *BTW* serves to educate the public on the characteristics and capabilities of this minority population (Leavitt, et al, 2015). Parasocial interaction serves as an interpersonal meeting between the viewer and the person seen on television (Perse & Rubin, 1989; Rubin & McHugh, 1987). This vicarious meeting and educational component can decrease social distance

by providing exposure to people with Down syndrome (Baumann, 2007). Additionally, *BTW* seems to be offering vicarious social support for parents of children with Down syndrome. Future study is needed to determine the depth and nature of parasocial interaction and social support in *BTW*. Although reality television provides a platform for real people to share real stories, editing, the agenda of producers, and the need for viewers can taint a show's original purpose. More study is needed to determine viewer reactions to these changes. All in all, *BTW*'s authentic positive representation of Down syndrome is challenging stereotypical media depictions and has the ability to provide education and to influence public perceptions and attitudes, about people with Down syndrome.





## Chapter 5: Conclusion

*BTW* provides a representation of Down syndrome that is not steeped in stereotypes but in experiences of those who have Down syndrome and those who are closely associated with Down syndrome. The limitations of the current study, including coder validity and unclear episode introductions and conclusions, are discussed below. *BTW* is changing the way people with Down syndrome are depicted in the media and, in turn, is rewriting the label of limitations that has long been associated with Down syndrome. However, future study is needed to determine the size of the role *BTW* plays in social support and attitude influence.

### Limitations and Future Research

While the findings of this study are significant, this study was not without limitations. This study used qualitative analysis by one researcher to uncover what messages *BTW* was providing in their representation of Down syndrome. This one-sided analysis was not subject to coder validity and thus is based on the perception and understandings of one researcher. Additionally, the unclear nature of *BTW*'s episode introductions and conclusions creates the possibility that some episodes introductions and conclusions were included in the data or that some scenes were perceived to be part of the episode when in reality they were a part of an episode introduction or conclusion sequence and thus not included in the data. The researcher has conducted previous research on media representations of Down syndrome and has been actively involved in issues related to people with disabilities. The researcher is not a member of the disabled community and therefore, is unable to completely understand the research subjects or the impact of certain scenes or stereotypes represented in *BTW*. The researcher has connections to the Deaf community but does not have close connections to someone with Down syndrome. All of these factors influenced the researcher's worldview and perspective which in turn influenced the data

collection and analyzation process.

This is the first study to assess *BTW*'s messages and impact on public perception. Future research is needed to assess the influence of parasocial interaction on social distance and social support. Moreover, the words authentic (Tsay-Vogel & Schwartz, 2014) and realistic (Hall, 2003; Giles, 2002) seemed to be defined similarly and used interchangeably in many studies. However, these words are not quite the same; authentic representations of disability can occur in fantasy settings and realistic representations of people with disabilities are depictions that closely mirror real life. Additionally, more research is needed on how reality television generally, and reality television docu-series shows specifically, shape and influence public perceptions. It would be interesting to note if there is a difference between audience perception of reality, in reality, television shows and the perception of reality in reality docu-series. While each of the seven adults featured in *BTW* are considered to be a part of a minority group due to their disability, three minority races including African American, Hispanic, and Japanese are represented amongst the cast. The racial, disability, and gender minority groups each carry their own unique stigmas and stereotypes. Thus, the connection to multiple minority groups results in multiple layers of stigma. Future researchers should explore these multiple layers of stigma and how they impact the representations in *BTW*. Finally, an assessment of *BTW*'s main viewers would also be beneficial to determine the true reach of *BTW*'s messages. Since *BTW* viewers can contact adults with Down syndrome and their parents featured in *BTW*, future studies should investigate the attitudinal influence of parasocial interactions that occur both through television watching and contact with characters on social media. Viewer perception of *BTW*'s realistic portrayal of Down syndrome and its subsequent related topics would be beneficial to understanding the strength of influence *BTW* has on frequent viewers.

## Conclusion

The unique nature of *BTW*'s representation is the ability to portray issues and truths about Down syndrome without stereotyping the individuals or the syndrome. Stereotypes such as villain, super crip, abnormal sexuality/asexual, monster, pitiful, maladjusted, worthless, burdensome and confinement, ultimately dehumanized individuals with disabilities (Harnett, 2000; Hayes & Black, 2003). By depicting people with Down syndrome as autonomous, sexually capable, multifaceted human beings with dreams, worries, and abilities, *BTW* is recognizing the humanity of people with disabilities and thus challenging stereotypical representations of this population. Instead of presenting a sugar-coated version of Down syndrome, *BTW* reveals that though people with Down syndrome have strengths and weaknesses, they are at their core human. While this television show is not without faults, *BTW*'s holistically human message creates a positive depiction of Down syndrome that can influence attitudes and beliefs and provides education for viewers (Hayes & Black, 2003; Schiappa, Gregg, & Hewes, 2006). The implications for parasocial interaction and *BTW* could provide hope for a child with Down syndrome's future and hope for de-stigmatization of individuals with Down syndrome. Instead of hiding Down syndrome, *BTW* flips the Down syndrome side up, with pride for the world to see.



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## **Appendix A**

### **Common Stereotypes Associated with Down Syndrome**

The following stereotypes have been compiled from 2 Down syndrome associations. The stereotypes from each source have been grouped and duplicates have been combined. While this is by no means an exhaustive list, these stereotypes represent a comprehensive list as reported by two large informational hubs associated with Down syndrome. The stereotypes have been compiled into relevant categories to aid readability.

#### **Scientific Knowledge.**

- a. It is very rare to meet someone with Down syndrome or meet someone who has this Down syndrome” (National Down Syndrome Society, 2015).
- b. “Scientists know everything there is to know about Down syndrome” (National Down Syndrome Society, 2015).

#### **Family Impact.**

- a. Everyone who has Down syndrome look exactly the same (Global Down Syndrome Foundation, 2017a).
- b. Down syndrome is the result of old age or parental misconduct or is the result of family heritage (Global Down Syndrome Foundation, 2017a; National Down Syndrome Society, 2015).
- c. “A child with Down syndrome will ruin a marriage” (Global Down Syndrome Foundation, 2017a).
- d. “A child with Down syndrome negatively impacts their siblings” (Global Down Syndrome Foundation, 2017a).

- e. People in the community will not support parents with children who have Down syndrome (National Down Syndrome Society, 2015).

**Mental Capabilities.**

- a. Everyone who has Down syndrome experiences severe intellectual issues (National Down Syndrome Society, 2015).
- b. Down syndrome limits a person's ability to read or write (Global Down Syndrome Foundation, 2017a).
- c. People who have Down syndrome are incapable of memorizing or recalling basic facts (Global Down Syndrome Foundation, 2017a).
- d. Adults with Down syndrome have the same capabilities as children with Down syndrome (National Down Syndrome Society, 2015).
- e. "People who have Down syndrome are always happy" (Global Down Syndrome Foundation, 2017a; National Down Syndrome Society, 2015).
- f. The words you use when talking to an individual with Down syndrome do not really matter. You can use words like "retarded" without fear of hurting any feelings (National Down Syndrome Society, 2015).

**Physical Health.**

- a. Everyone who has Down syndrome is constantly sick and will develop sicknesses such as Alzheimer's disease (Global Down Syndrome Foundation, 2017a; National Down Syndrome Society, 2015).
- b. All individuals with Down syndrome are always obese (Global Down Syndrome Foundation, 2017a).

- c. Individuals with Down syndrome do not feel pain the way that people without Down syndrome do (Global Down Syndrome Foundation, 2017a).
- d. People with Down syndrome do not have proper motor function in their legs and will never be able to play sports (Global Down Syndrome Foundation, 2017a).
- e. Individuals with Down syndrome do not live very long (Global Down Syndrome Foundation, 2017a).

**Quality of Life.**

- a. Individuals with Down syndrome cannot attend a mainstream public school (Global Down Syndrome Foundation, 2017a; National Down Syndrome Society, 2015).
- b. Adults with Down syndrome cannot get married (National Down Syndrome Society, 2015).
- c. Adults with Down syndrome are unable to be independent or to live independently and are unable to obtain and keep a job and thus unable to contribute or be an active member of society. (Global Down Syndrome Foundation, 2017a; National Down Syndrome Society, 2015).
- d. Down syndrome limits people to a childless existence (Global Down Syndrome Foundation, 2017a).



## Appendix B

### The Adults with Down Syndrome and their Familial Connections

Compiled below are the people with Down syndrome featured in *BTW*. Also included are their corresponding ages as reported in their first show appearance and the names of their parents.



a) Cristina

Age 25

Mariano (Dad)

Beatriz (Mom)



b) Elena

Age 28

Stephen (Dad)

Hiromi (Mom)



c) John

Age 28

John Sr. (Dad)

Joyce (Mom)



d) Megan

Age 22

Kris (Mom)



e) Rachel

Age 32

Gary (Dad)

Rachel (Mom)



f) Sean

Age 21

Rick (Dad)

Sandra (Mom)

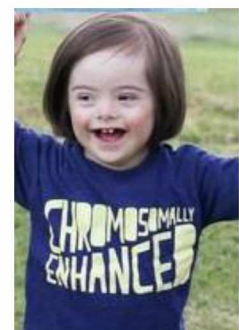


g) Steven

Age 24

David (Dad)

Claudia (Mom)



h) Rocco

Age 2 (nearly 3)

Chris (Dad)

Amy (Mom)

Figure 1.1 (a-g), *BTW* Cast, (n.d.). (h), Sullivan, 2017

## **Photographic References**

*BTW* Cast [Digital image]. (n.d.). Retrieved from <https://www.yidio.com/show/born-this-way>

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